

LEARNING MADE EASY



AARP[®]

Portable Edition

Navigating Your Later Years

**for
dummies**[®]
A Wiley Brand



Create a plan
for your later years

Make important housing
and healthcare decisions

Manage your money
and legal affairs

Carol Levine

Director, Families and Health Care
Project, United Hospital Fund



Navigating Your Later Years

Portable Edition

by Carol Levine

AARP®

**for
dummies®**
A Wiley Brand

Navigating Your Later Years For Dummies®, Portable Edition

Published by:

John Wiley & Sons, Inc., 111 River Street, Hoboken, NJ 07030-5774

www.wiley.com

Copyright © 2021 by AARP. All rights reserved. AARP is a registered trademark.

Published simultaneously in Canada

No part of this publication may be reproduced, stored in a retrieval system or transmitted in any form or by any means, electronic, mechanical, photocopying, recording, scanning or otherwise, except as permitted under Sections 107 or 108 of the 1976 United States Copyright Act, without the prior written permission of the Publisher. Requests to the Publisher for permission should be addressed to the Permissions Department, John Wiley & Sons, Inc., 111 River Street, Hoboken, NJ 07030, (201) 748-6011, fax (201) 748-6008, or online at <http://www.wiley.com/go/permissions>.

Trademarks: Wiley, For Dummies, the Dummies Man logo, Dummies.com, Making Everything Easier, and related trade dress are trademarks or registered trademarks of John Wiley & Sons, Inc., and may not be used without written permission. AARP is a registered trademark of AARP, Inc. All other trademarks are the property of their respective owners. John Wiley & Sons, Inc., is not associated with any product or vendor mentioned in this book.

LIMIT OF LIABILITY/DISCLAIMER OF WARRANTY: WHILE THE PUBLISHER AND AUTHOR HAVE USED THEIR BEST EFFORTS IN PREPARING THIS BOOK, THEY MAKE NO REPRESENTATIONS OR WARRANTIES WITH RESPECT TO THE ACCURACY OR COMPLETENESS OF THE CONTENTS OF THIS BOOK AND SPECIFICALLY DISCLAIM ANY IMPLIED WARRANTIES OF MERCHANTABILITY OR FITNESS FOR A PARTICULAR PURPOSE. NO WARRANTY MAY BE CREATED OR EXTENDED BY SALES REPRESENTATIVES OR WRITTEN SALES MATERIALS. THE ADVICE AND STRATEGIES CONTAINED HEREIN MAY NOT BE SUITABLE FOR YOUR SITUATION. YOU SHOULD CONSULT WITH A PROFESSIONAL WHERE APPROPRIATE. IF PROFESSIONAL ASSISTANCE IS REQUIRED, THE SERVICES OF A COMPETENT PROFESSIONAL PERSON SHOULD BE SOUGHT. THE PUBLISHER, AARP, AND THE AUTHOR SHALL NOT BE LIABLE FOR DAMAGES ARISING HEREFROM. THE FACT THAT AN ORGANIZATION OR WEBSITE IS REFERRED TO IN THIS WORK AS A CITATION AND/OR A POTENTIAL SOURCE OF FURTHER INFORMATION DOES NOT MEAN THAT THE PUBLISHER, AARP, OR THE AUTHOR ENDORSE THE INFORMATION THE ORGANIZATION OR WEBSITE MAY PROVIDE OR RECOMMENDATIONS IT MAY MAKE. FURTHER, READERS SHOULD BE AWARE THAT INTERNET WEBSITES LISTED IN THIS WORK MAY HAVE CHANGED OR DISAPPEARED BETWEEN WHEN THIS WORK WAS WRITTEN AND WHEN IT IS READ.

For general information on our other products and services, please contact our Customer Care Department within the U.S. at 877-762-2974, outside the U.S. at 317-572-3993, or fax 317-572-4002. For technical support, please visit <https://hub.wiley.com/community/support/dummies>.

Wiley publishes in a variety of print and electronic formats and by print-on-demand. Some material included with standard print versions of this book may not be included in e-books or in print-on-demand. If this book refers to media such as a CD or DVD that is not included in the version you purchased, you may download this material at <http://booksupport.wiley.com>. For more information about Wiley products, visit www.wiley.com.

Library of Congress Control Number: 2020952024

ISBN 978-1-119-80984-5 (pbk); ISBN 978-1-119-81015-5 (ebk)

Manufactured in the United States of America

10 9 8 7 6 5 4 3 2 1

Contents at a Glance

Introduction	1
CHAPTER 1: Thinking about the Big Picture and the Future.....	5
CHAPTER 2: A Personal Inventory: Past, Present, and Future	15
CHAPTER 3: Fond of the Familiar: Staying in Your Home.....	25
CHAPTER 4: Downsizing for Now and Later	39
CHAPTER 5: Assisted and Independent Living and Other Group Settings	47
CHAPTER 6: Getting Around: Transportation Options.....	63
CHAPTER 7: Unraveling the Rules of Medicare and Medicaid	77
CHAPTER 8: Financial Matters: Money Management and Wills	95
CHAPTER 9: Choosing Good Medical Care	107
CHAPTER 10: Understanding the Different Roles of Nursing Homes.....	123
CHAPTER 11: Getting the Healthcare You Want (and Avoiding What You Don't Want).....	137
CHAPTER 12: Ten (Plus Six) Resources to Help You Navigate Your Later Years	151
Index	157

Table of Contents

INTRODUCTION	1
About This Book	1
Foolish Assumptions	3
Icons Used in This Book	3
Where to Go from Here	4
 CHAPTER 1: Thinking about the Big Picture and the Future	5
Planning for the Future Starts with You	5
Creating a Plan for the Future Now	6
Discovering How Your Options Are Changing	8
Money is a factor	8
Legal reasons	9
People want change	10
Meeting Your Changing Needs	10
Location, location, location	11
Timing and flexibility	12
Getting Professional Advice	13
 CHAPTER 2: A Personal Inventory: Past, Present, and Future	15
Looking at the Present — and the Future	16
Healthcare needs	16
Family, friends, and professionals	18
Personality characteristics	19
Attitudes about money	21
Creating a Plan Based on Your Profile	23
 CHAPTER 3: Fond of the Familiar: Staying in Your Home	25
Staying at Home in Your Community	25
Dealing with Two Major Hazards	26
Preventing falls	27
Preventing burns	29
Modifying a Home	29
Categorizing types of home modifications	30
Checking out accessibility	31

Finding a contractor	33
Getting help paying for home modifications.....	34
Seeking Help at Home	35
Allocating tasks to family	35
Searching for services	36
Finding help for other chores.....	37
Putting technology to use	37
CHAPTER 4: Downsizing for Now and Later	39
The Emotional Aspects of Downsizing.....	40
Downsizing and Home Renovations	41
Getting Started	41
Putting together important papers	42
Sorting and decision making.....	42
Donating or selling items	43
Making the Move.....	45
CHAPTER 5: Assisted and Independent Living and Other Group Settings.....	47
What Is Assisted Living?	48
Knowing other terms for “assisted living”	48
Getting to know what assisted living offers.....	49
Checking out healthcare services	51
Finding more information on assisted-living facilities	52
Evaluating the Cost of Assisted Living	53
Choosing from the menu of cost plans.....	54
Asking questions to create a monthly budget.....	56
Beyond the Brochure: What to Look for When You Visit	57
Making notes about the common areas.....	57
Checking out the residential units	58
Investigating continuing care	59
Independent Living and Other Options for Group Living	59
Independent living for seniors	60
Affinity or niche communities	60
Cohousing arrangements	61
House sharing	61
Group homes	62

CHAPTER 6:	Getting Around: Transportation Options	63
	Judging Whether Driving Is Still Safe	64
	Watching for warning signs of unsafe driving	64
	Starting the conversation	66
	Making Your Car Fit You	67
	Increasing safety with new technology	68
	Choosing a new vehicle	69
	Modifying vehicles	69
	Knowing When It's Time to Give Up the Keys	70
	Finding Alternatives to Driving	71
	Public transportation and paratransit options	72
	Private options	74
 CHAPTER 7:	 Unraveling the Rules of Medicare and Medicaid	 77
	The Distinction between Medicare and Medicaid	78
	Looking at Medicare Basics	79
	Are you eligible for Medicare?	79
	What's included in Original Medicare	80
	What you get with Medicare Advantage plans	83
	Prescription drug coverage	84
	Durable medical equipment coverage	86
	Home healthcare services	87
	Medicaid Ground Rules	88
	Are you eligible for Medicaid?	89
	What services Medicaid offers	91
	How Medicaid works with home- and community-based programs	92
	Medicaid managed long-term care	93
 CHAPTER 8:	 Financial Matters: Money Management and Wills	 95
	Managing Money	96
	Opening joint bank accounts	96
	Granting financial powers of attorney	98
	Where There's a Will . . .	100
	Taking inventory of your assets	101
	Considering types of wills	102
	Choosing the executor	103
	Taking the final steps	103
	Settling the Estate with Probate	104

CHAPTER 9:	Choosing Good Medical Care.....	107
	Checking on the Special Medical Needs of Older Adults.....	108
	Identifying common chronic conditions	108
	Dealing with multiple ailments.....	110
	Finding the Right Specialist to Manage Care.....	111
	Considering the need for a geriatrician	111
	Finding a geriatrician	112
	Navigating Hospitals	113
	Where to go for emergencies and non-emergencies.....	114
	Being admitted to the hospital.....	115
	Planning for a hospital stay	117
	Polypharmacy: Too Many Drugs?.....	119
	Using caution with certain drugs	120
	Getting medications right	121
 CHAPTER 10:	 Understanding the Different Roles of Nursing Homes.....	 123
	Beginning with Nursing Home Basics	124
	Defining nursing homes.....	124
	Moving from a hospital to short-term rehab	125
	Comparing nursing homes for a long stay	127
	Visiting Nursing Homes	128
	Checking off important points	129
	Noting policy details	133
	Responding to Residents' Problems in Nursing Homes	134
 CHAPTER 11:	 Getting the Healthcare You Want (and Avoiding What You Don't Want).....	 137
	Talking about Future Healthcare Decisions	138
	Realizing the importance of advance planning.....	138
	Making wishes known with advance directives and living wills	139
	Dealing with the Rules of Advance Directives.....	140
	Finding the forms for advance directives and living wills	140
	Putting your wishes down on paper.....	141
	Choosing a healthcare proxy.....	141
	Adding do not resuscitate (DNR) orders	142
	Keeping your advance directive accessible	143
	Choosing Physician Orders for Life-Sustaining Treatment (POLST).....	144

Understanding Care Options for Serious Illness:	
Palliative Care and Hospice.....	145
Palliative care.....	146
Hospice.....	147
CHAPTER 12: Ten (Plus Six) Resources to Help You	
Navigate Your Later Years.....	151
Checking Out Federal Programs.....	151
Medicare and Medicaid.....	152
Other federal agencies.....	153
Getting Information through State and Local Programs.....	154
Turning to Community-Based Organizations	155
INDEX.....	157

Introduction

If you've opened this book, then you're thinking about how best to navigate this next stage of life, whether for yourself or for a relative. (For simplicity, I'll refer to "you" in most places in the book.) Here, you find a road map to move forward, step by step.

Because you've picked up this book, you know you have questions. What you may not know is the broad scope of decisions, services, and choices that may arise. In my many years in the fields of health policy, aging, and family caregiving, I have seen that people often start with a specific question about topics such as selecting the right healthcare insurance or choosing an independent- or assisted-living facility and soon find that they need to explore many other avenues as they pursue their goals of good health, independence, choice, and quality of life.

Times have changed, and there are many more options than there were decades ago, so keep an open mind. Learning about these options can be challenging, but finding the answers you need and creating a comprehensive and workable plan that fits your needs are well worth the effort. Like any other major decision in life, planning requires weighing risks and benefits, being flexible, and staying open to change. It can be unsettling. Some of your assumptions and preconceptions may be challenged. Even though I have many years of experience in this field, writing this book has given me new insights into the difficulties that individuals and families face in planning. I have new respect for their diligence and devotion.

About This Book

I wrote this book to offer the broadest possible view as well as to provide information about specific topics. You'll find out about

- » Modifications you can make to your home so you can stay independent and live at home as you age
- » Downsizing your current home or planned move
- » Options for housing such as independent and assisted living

- » Transportation and other community services
- » Medical care, which may be primary care, preventive care, hospitalization, or rehabilitation services
- » Financial issues and tips for managing money
- » Advance directives so your wishes concerning healthcare are known
- » Wills

Throughout this book, I present you with a range of options to consider, always with the caveat that no one solution works for everyone. You may, for instance, need to make modest adjustments to your home, or you may need to move to an assisted-living community. I also include your family, partner, neighbors, and friends — and the community in which you live — as crucial factors in decision making. Remember too that the emotional aspects of a plan are often underestimated but can determine its success or failure.

I've read and contributed to many books that tackle one subject at a time. They are valuable resources but don't cover the wide landscape. This book is a blend of what I've learned from all these approaches, but it presents the big picture and then zeroes in on the practical, hands-on information that is often difficult to find in one place.

You, the reader, decide how to use this book. It is organized so you can easily find the topics you want to know more about and skip the ones that don't apply to your situation.

Every chapter has web links to other resources to help you get more specific information about a particular topic, find information about your state's regulations, or delve deeper. You may note that some web addresses break across two lines of text. If you're reading this book in print and want to visit one of these web pages, simply key in the web address exactly as it's noted in the text, pretending that the line break doesn't exist. If you're reading this as an e-book, just click the web address to be taken directly to the web page.

This book is meant to serve as a reference, so you don't have to commit any information to memory. It's all there, waiting to be read and reread.

Additionally, two other *For Dummies* books from AARP — *Social Security For Dummies* (by Jonathan Peterson, published by Wiley) and *Medicare For Dummies* (by Patricia Barry, published by Wiley) — are helpful adjuncts to this book and offer more detail about those two important public programs.

Foolish Assumptions

This book makes a few assumptions about you, the reader:

- » You probably don't know a whole lot about various aspects of housing, finances, legal directives, and medical coverage you'll want or need to consider as you age. And even if you have some professional or personal background in the field, you can benefit from new information and different perspectives.
- » You may be starting to plan, or already planning, for yourself or your spouse or partner. You probably have some time to plan before the need arises — but don't underestimate how long it may take.
- » You may be starting to plan, or already planning, for an older person such as a parent. The time for planning in this situation may be short; it may follow a health crisis. You need help now. But don't make quick decisions that will be hard to reverse.
- » You may be comfortable using the Internet to find additional resources.
- » You are worried about making the best choices and how to pay for them. Rest easy: You are not alone.

Icons Used in This Book

Throughout the book, you will see several icons that draw your attention to certain kinds of information.



TIP

The Tip icon links to an additional resource or offers advice about the topic discussed in the preceding text.



REMEMBER

The Remember icon is not a literal order to memorize the information but a word to the wise, a reminder of what you should be considering.



WARNING

The Warning icon signals important information that alerts you to a potential problem — for example, a fraudulent practice or a scam aimed at older adults.

Where to Go from Here

With all the flexibility inherent in the *For Dummies* format, where should you start? If you know you want information about a specific topic (for example, advance directives), by all means use the table of contents and index to find those sections. If you're still getting your head around the idea of making long-range plans, pick a chapter that interests you and dig in. You don't even have to start at the beginning of that chapter. But remember what Maria in *The Sound of Music* told her young pupils: The beginning is a very good place to start.

- » Planning now for what you may need in the future
- » Clarifying options and needs
- » Selecting good advisers

Chapter 1

Thinking about the Big Picture and the Future

Just by opening this book, you have become a member of a select group of people who are taking a big step toward a better future for yourself and your family. Most studies show that only a third of Americans have made even the most basic plans to prepare or pay for their future needs. Studies show that few older Americans have done substantial planning or saving for their future needs.

Thinking about the many aspects to consider — from finances to housing to healthcare and more — may be challenging because the choices available are often complex. They may involve myriad financial calculations as well as personal and family preferences. But planning today lets you envision the tomorrow of your choice and make it happen. In this chapter, I help you start to think about future needs in a proactive, calm, and positive way.

Planning for the Future Starts with You



REMEMBER

Future care is different for each individual, tailored to a person's needs and preferences. Your plans do not start with a place or a payment mechanism or a set of services; they start with a person.

Planning should also start early. You'll want to start to think about housing, for instance, at a point when you have various options — whether at home or in a community — that prolong independence and make it less likely that institutional care will later be needed. From that perspective, modifying, and downsizing your home to make it safer and more accessible may be part of your plan. Transportation options are critical to the success of your plan.

Now is also the time to think about the important issues of financial and legal planning. What will Medicare pay for? What are the eligibility criteria for Medicaid? What steps can you take to draw up a will and other legal documents when you are healthy and able to make your preferences known?

Another consideration is managing your healthcare, from choosing a doctor to understanding the changes in skilled nursing facilities that are making these facilities more home-like and person-centered.

Creating a Plan for the Future Now

Aging is a reality. And an undeniable part of that reality is that most people, especially those who live to an advanced age, will need assistance in some aspects of their lives. If you are 65, you have nearly a 70 percent chance of needing some type of extended care and support at some future point, according to the U.S. Department of Health and Human Services. One-third of 65-year-olds may never need it, but 20 percent will need it for more than 5 years.

Yet what is undeniable in terms of demographics is easily deniable when it comes to anticipating our own lives and those of our older family members. About half of Americans over the age of 40 believe that “almost everyone” is likely to require long-term care at some point, but only a quarter think they themselves will need it, according to a 2016 survey conducted by the Associated Press-NORC Center for Public Affairs Research.

I can check off quite a few reasons for delaying the planning process, but there are just as many benefits to starting now.

Decisions made in a crisis are often hasty and ill-considered. This is true in many aspects of life but is particularly problematic when a person's health and well-being are at stake. Not all crises can be avoided, but when they do occur, having a plan in place reduces the likelihood of the most severe unintended consequences.

For example, an important part of a plan is having an advance directive and identifying a healthcare proxy (a person legally authorized to speak for you; see Chapter 11 for more information). In a medical emergency where you can't speak for yourself, an advance directive and a healthcare proxy can make it more likely that you get the types of treatment you want and — even more difficult to achieve — don't get what you don't want. Certainly, it can be hard to think about this kind of situation, but the alternative is worse. Without some form of advance directive, no one will know what you want or don't want, and it will be unclear who has the authority to speak for you. If your family members can't agree, the decision will be made by strangers, and in the worst-case scenario, there will be litigation. The effort involved in planning ahead is minimal compared to the consequences of not doing so.

This example also underscores another benefit of planning: making decisions for yourself instead of leaving them to others or to chance. Having absolute control is unrealistic and possibly even undesirable, but letting family and other intimates know your values and preferences about treatment goals leaves more in your hands.

Some families are used to discussing and even arguing about all sorts of things, from trivial to significant. Others avoid conversations about serious matters. You can't change family dynamics that developed over years, but you can work within that framework to make your wishes known and to anticipate objections. Sometimes you may have to make some compromises, such as limiting when and where you drive or accepting some help at home. In other situations, your family may have to accept a less-than-perfect living situation out of respect for your wishes, such as staying in your own home. If you and your family can negotiate these bumps, you are all less likely to find yourselves in opposite camps when it comes to making major decisions.



Planning ahead also allows you to investigate more choices more thoroughly. You will still have hard decisions to make, but you will have the benefit of information, discussion, and time. Still, your planning should be flexible. Try to build in as many alternatives as possible to allow for changes in health, finances, family situations, and all the other elements that can make a difference.

Discovering How Your Options Are Changing

Your options for the future are expanding — and that’s a good thing. There are many more alternatives for living at home or in the community, where the clear majority of people want to be. Technology is making it possible to have your healthcare monitored at home and to keep you in touch with family and friends. There is a greater awareness of the importance of a stimulating environment and social connections for mental and physical health.

Skilled nursing facilities are changing too, as they move toward a more person-centered focus and introduce elements of stimulating activity and participation for their long-stay residents. There are several reasons for these changes in the landscape.

Money is a factor

One reason is economic: Medicaid — the federal-state program for low-income people — is the major payer of nursing homes and community-based services, and policymakers want to keep those costs in check. According to the government website [Medicaid.gov](https://www.medicaid.gov), about 20 percent of Medicaid spending (\$623 billion in fiscal year 2019) goes to long-term care. Long-term-care payments cover nursing homes, care facilities for individuals with intellectual disabilities, and home health care, among other services.

To keep this spending in check, Medicaid has tried to move away from what has been called an “institutional bias,” which means that the bulk of funding goes toward skilled nursing facilities, putting it instead toward more community-based care. In 1995, for example, 80 percent of Medicaid spending on long-term care was for institutional care; by 2011 that percentage had dropped

to 55 percent. Spending on home and community-based services surpassed spending on institutional care for the first time in 2013 and now comprises 57 percent of total Medicaid long-term-care spending. Community-based care is typically cheaper than skilled nursing facility care, which makes it attractive to Medicaid programs faced with escalating costs, and it is also preferred by individuals.

Legal reasons

The federal Americans with Disabilities Act (ADA) is another reason for changes. In 1999, the U.S. Supreme Court held in *Olmstead v. L.C.* that unjustified segregation of people with disabilities in nursing homes constitutes discrimination in violation of Title II of the ADA. The court held that public programs such as Medicaid must offer community-based services to people with disabilities when such services are appropriate, the affected person doesn't oppose community-based treatment, and community-based services can be reasonably accommodated, considering the resources available and the needs of others who are receiving disability services from the entity.

In its ruling, the Supreme Court explained that “institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable of or unworthy of participating in community life.” Furthermore, “confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.” Although the case that reached the Supreme Court was about two young people with mental disabilities, the *Olmstead* decision applies to people of all ages and all different kinds of disabilities.

While the *Olmstead* ruling is limited to a defined group of nursing-home residents, it acts as an incentive for federal and state programs to develop appropriate community-based alternatives to institutions, which may benefit a larger group of people. It also reaffirms the importance of consumer choice in long-term care.

People want change

In addition to economic incentives and legal rulings, consumer demand has also played a part in moving away from old forms of long-term care — think traditional skilled nursing homes — to more home-like and person-centered settings. As people live longer — often into their 90s and beyond — the length of time a person needs various forms of care has increased and has required accommodation to various levels of need.

Although the trends of home-like and person-centered settings are positive, implementation across the country is inconsistent and variable. At best, the system is a patchwork quilt of settings and services, some strong and some weak, with different eligibility requirements and payment sources. But compared to a few decades ago, the quilt itself is bigger because people have demanded better options.

Meeting Your Changing Needs

Planning should be a dynamic process. Where you want to live in your 60s may look very different from where you'll want to be in your 80s. Your needs change based on your finances, family circumstances, health, and more. Someone considering moving from a single-family house to an apartment or assisted-living facility should think about whether this is a move that can satisfy future needs as well as immediate ones. Not everyone moves through the spectrum of needs at the same pace, or even goes through all the same stages. The needs of a person with mild cognitive impairment, for instance, are very different from the needs of a person with advanced dementia. As another example, someone diagnosed with diabetes needs chronic care — that is, doctor or nurse visits; ongoing monitoring, including blood tests; medications; and foot and vision exams. If the diabetic condition deteriorates to the point where the person is unable to walk or perform daily activities independently, then significant changes need to be made.

Some future needs can be anticipated, and others cannot. The goal is not to have a detailed plan for every possible contingency but a general idea of what can reasonably be anticipated and planned for.

Location, location, location

The well-worn real estate adage of choosing a home based on location applies to this stage of your life as well. In this case, location is not so much an economic asset (although in some cases it can be) as a symbol of personal comfort and satisfaction and, often, being near family and close friends. Consider how you will meet all your needs — including the social and emotional aspects.

Many people just say, “I want to stay in my own home!” And indeed, that’s a reasonable short-term goal, but it may not be feasible in the long run. Beyond their initial statement, many people just stop thinking about it or assume that their children (or more likely, a particular child) will say, “I’ll move in with you so you can stay at home.” Maybe that will happen, and maybe it won’t. But it certainly requires an explicit understanding, not just an assumption.

In thinking about location, you want to consider:

- » **Family:** Moving to another community to be nearer children, often at their urging, may be an option. You should consider what you may lose and what you may gain. Someone with strong ties to a particular community — for example, a faith community or club or other group — may miss that connection. On the other hand, you may be able to re-create those ties in another setting. A lot depends on the type of community you would move to, whether you have spent enough time there to be confident you would like it, and whether you will have to depend on your children for transportation and other needs. Visiting your children as a guest and participating in their activities is different from being a permanent resident. Some social groups welcome newcomers, but others closed their ranks a long time ago.
- » **Climate:** It’s almost a stereotype that older people want to move to warmer places, but in fact that is one main reason people do relocate. There may be health reasons to move to a different climate, or the upkeep on a house and car in a winter zone may be too onerous to sustain. But not everyone adjusts easily to a more or less constant temperature, especially if it’s very hot. And although blizzards can create dangerous situations for someone living alone, so can hurricanes and tornados, which generally occur in warmer areas.

» **Cost of living:** Different regions of the country are more or less expensive places to live. This applies to costs of housing, medical care, food, personal care services, transportation, and other items that will figure into your plan as well as independent or assisted living.



TIP

An extended visit to a community you're considering is a good way to find out whether you like it. Before or after your visit, you can look online to get an idea of prices for everything from groceries to rentals. You'll also see what social, sporting, and cultural events are featured. Think about what you most like to do now and what you would like to be able to do in a new location.

Timing and flexibility

If you're going to make a change, when is the best time to do it? I can't give you the perfect answer. Still, if you're planning to stay where you are for the immediate future, you should start now to reassess your home for safety and accessibility. The mostly minor modifications you can make now (see Chapter 3) will help prevent falls, which are the most common reason for a need for more intense long-term care services. Even if you don't expect to stay in this location permanently, the modifications will add value to your home because they will also make it safer for others, including families with young children.

At the same time, you should begin to investigate alternatives. Without the pressure of family members or doctors insisting that you make a change, you can think about what matters most to you and what you have become used to but can live without.



REMEMBER

If a change does fit into your plan, allow enough time to make all the arrangements and consider all the pieces that need to be reassembled in a new location, whether that is independent living, assisted living, or another option. Downsizing and moving is one of life's most stressful events, even if it is well-planned and desired. Take your time.

You may not have enough space in your new location for the lifetime of memorabilia and objects you have collected. You may have to donate or sell some possessions. If you're moving from a big house to a smaller house, apartment, or condo, you may have to decide what furniture to keep and what won't work in the new setting. This process — with the emotional impact of dealing with

so many memories at once — stops many people from moving forward. But if you enlist help from family or friends, it can be liberating. (See Chapter 4 for more information.)



REMEMBER

Be flexible. Even if you aren't moving to a different location or a different community, you're entering a new stage of life. Change can be stimulating but also disorienting.

Paradoxically, remaining independent often means asking for help. Asking for and accepting help is often a major hurdle in any future plan. Being willing to acknowledge that you can't do everything alone (and probably you never really did) is the first step toward a person-centered plan. Family and friends are your first sources of help, but they are not the only ones. Neighbors, volunteers from community groups, building contractors, home care aides, and transportation services can all play a part in helping you achieve your goals.

Getting Professional Advice

Among the people you may need to consult as you navigate this path are professionals such as doctors, lawyers, and accountants. These professionals can help you make realistic plans and avoid costly and potentially damaging errors.

Choosing these advisers can be tricky. Your niece who just graduated from law school may offer to help you write a will, but she lives in a different state and doesn't know the law in your state. You have some investments with a local broker, and you have done well with his recommendations. But he has a financial interest in guiding you toward certain choices, which may not serve you well as you contemplate the future. And even your doctor, who has taken care of you for years, sees you as you are, not necessarily as you may become. She may or may not be the best person to give you a completely honest appraisal of your health outlook for the future.

These people may be competent advisers. It makes sense, however, to consult with others so you can be sure you're getting objective and accurate information.

For example, you may want to ask for a geriatric evaluation from a physician who is experienced in caring for older adults, whose course of illness and reactions to medications may differ significantly from younger people. An attorney who specializes in elder law has particular expertise and can guide you toward creating documents that contain the precise instructions you want. And a financial adviser who charges a fee but does not gain from your investment choices may be a good person to help work out the financial aspects of your plan.

When considering using the services of a specific professional, ask about the following issues before moving forward:

- » Experience with working with clients with similar needs
- » Length of time in practice
- » Recommendations
- » Fees for the service



REMEMBER

Even with good advisers, you need to be intimately involved in all decisions (or have a family member do this on your behalf). The investment of your time and money helps ensure that you get the kind of future care you want.

- » Assessing the present and the future
- » Putting together a profile

Chapter 2

A Personal Inventory: Past, Present, and Future

Your vision of your future reflects you as you are now and what you have experienced in the past. A lot depends on your current health status and anticipated future needs, of course, and your preferences for assistance in managing day-to-day activities. Finances are an important part of the equation as well.

But two people with the same health and financial profile may want to live in different types of settings and receive help in different ways. In this chapter, I help you step back from short-term decisions and think about the kind of person you are and how you want to spend your time. If another person will be sharing this stage of life with you, you should both undertake this exercise. It may reveal some surprises as well as similarities in goals. If you're helping a parent or other older relative plan, you can encourage them to go through the process with your help. You'll get to know each other in new and possibly revealing ways. This chapter guides you through finding out what type of setting best suits your needs and lifestyle. It also helps you create a plan to steer you in the right direction for the future.

Looking at the Present — and the Future

Imagining what you'll be like in 10, 15, or 20 years is hard. But your life so far gives you some clues. What were you like 10, 15, or 20 years ago? Have you changed a lot, or is there a consistent pattern? Have you changed jobs or careers? Have you moved around the country or internationally? Have you been married, divorced, or widowed — more than once? Have your spending or savings habits changed? Or has your life gone along in more or less planned and predictable ways?

These questions aren't intended to be value judgments about one lifestyle versus another but simply a way for you to consider your tolerance for risk (or, if you prefer, adventure), need for stability, and comfort with change. In the following sections, I organize the inventory around four categories: healthcare needs; family, friends, and professionals; personality characteristics; and attitudes about money. Each is an important element in creating your personal profile.

Healthcare needs

Your overall health and any special considerations are clearly important aspects to consider not only on their own but because they will affect many aspects of the nonmedical assistance you may need.

Here are some questions to ask yourself. Be ruthlessly honest. No one else has to see your list unless you want to share. It is intended to give you a template to think about your healthcare needs and how they would be incorporated into a future plan:

- » How would you describe your overall health — poor, fair, good, excellent? Has this status changed in the past few years?
- » Do you have any chronic conditions? (Examples are high blood pressure, diabetes, arthritis, and heart problems.) What are they? Are they under control?
- » Is the condition expected to get worse as you age?
- » How many doctors do you see regularly? Are your appointments regularly scheduled checkups or as-needed visits? Do these doctors share information with each other and with you?

- » Do you see any other healthcare professionals — home care nurse, physical therapist, or chiropractor, for example?
- » Do any of your health conditions limit your ability to function at home or in the community?
- » Do you use mobility assistive devices of any kind — cane, walker, or wheelchair, for example?
- » How many prescription medications do you take?
- » How many over-the-counter (OTC) medications such as vitamins or aspirin do you take?
- » Do you have an up-to-date list of all your prescribed and OTC medications?
- » Does anyone help you with healthcare tasks such as giving injections, monitoring machines like oxygen tanks, or taking care of wounds? If so, who helps?
- » Have you had your vision and hearing checked in the past year?
- » Do you wear glasses or a hearing aid?
- » Do you smoke?
- » Do you drink alcohol or use recreational drugs? How often?
- » Do you see a dentist regularly?
- » Do you eat nutritious meals (most of the time)?
- » Have you fallen in the past year? Were you injured?
- » Do you have trouble sleeping?
- » Do you exercise regularly? Or at all?
- » Do you often feel sad or lonely?
- » Are you concerned about memory loss?
- » Do you have clear preferences about the kind of care you would want or not want if you were in a coma after extensive brain damage, or if you were not expected to recover from an illness?
- » Have you told anyone about these preferences and documented them in an advance directive?
- » Do you worry about your health? If you do, what worries you the most?



REMEMBER

Even this schematic outline should help you assess your current and potential future needs for healthcare. If you have generally good health and manage your healthcare needs with a minimum of professional involvement, then you should be able to maintain this level of healthcare wherever you are. But if you already have serious chronic health conditions that require frequent doctor visits and multiple medications, moving away from your regular source of care may present problems.

For example, a move to assisted living may appeal to you because of the attractive setting, the availability of meals and housekeeping services, and the promised activities. But most assisted-living facilities don't have the capacity to serve the medical needs of someone with serious chronic conditions, and the location may not be convenient to your usual doctors' offices. On the other hand, you may be able to maintain your current healthcare arrangements in an assisted-living facility. It's important to find out.



TIP

If you're thinking of moving to a nearby assisted-living facility where your contact with your regular healthcare providers can be maintained, it is a good idea to let them know of your plans and to ask whether they have any reservations about the idea. If you're thinking of moving far away, you can ask for referrals to providers in your new location. But remember that assisted-living facilities don't provide medical care, and you'll need to build that into your plan. Find out more about assisted living in Chapter 5.

Family, friends, and professionals

Healthcare may be a critical factor in your plans for the future, but it's not the only one. Just as important are your values and preferences about the kind of life you want to continue (or begin) to live.

This section asks for an inventory of the people in your life, what roles they play now, and how you would like them to participate if your needs for assistance grow.

- » Who do you consider your family? The people you include can be your spouse, parents, children, grandparents, siblings, cousins, or other relatives. They can also be domestic partners, companions, and other people with whom you have a very close relationship.

- Which of these people do you rely on most for emotional support and comfort?
- Who would you call first if you needed help in making a medical decision? Settling a financial problem? Talking about your will?
- Who lives closest to you? Or with you? Does distance present a problem in getting together regularly or on short notice? You may be able to discuss a problem with someone far away, but that person isn't going to be able to help in an emergency.
- Do any of these people rely on you for the same sorts of assistance? For example, financial support? Advice and counseling? Day-to-day assistance?
- How do you currently communicate with your family? Frequent visits? Phone? Email? Texts? Or only at special events?
- Are there tensions within your family about money, relationships, obligations, or other factors?
- Are there family members with whom you have no relationships that you would like to involve in your life?
- » Overall, how important is it to you to be close (geographically and emotionally) to your family?
- » Beyond family, do you have close friends who in some ways substitute for family or add to family support?
 - Can you call on them for the kinds of assistance that may be expected first from family?
 - What limits would you anticipate friends may place on assistance?
- » Do you have trusting relationships with professionals such as doctors, lawyers, accountants, clergy, and others who can advise you on medical, financial, or personal matters? If not, can you identify people who may fill these roles?

Personality characteristics

Having looked at your health status and your available family resources in the previous sections, now take a clear look at your own preferences and values. This is where you can list what is

important to you and what doesn't matter all that much. Again, be candid.

- » Does religion play an important role in your life? If so, does this mean going to religious services regularly and observing religious practices? Or is it a less organized but still significant influence guiding how you live? Or do you consider yourself a spiritual but not religious person?
- » If you're still employed, how important is your job to your sense of well-being? Would you miss that role? What in particular do you value?
- » If you are retired, do you miss any part of your working life? Or are there aspects of working that you don't miss at all?
- » Would you describe yourself as shy, outgoing, or somewhere in between?
- » Do you make friends easily?
- » Have you made any new friends in the past year?
- » Do you like everything to be neat and tidy? Does clutter bother you?
- » If you don't mind clutter, does it result in what some people may call a total mess or hoarding?
- » Do you like to be around animals? Have you always had pets? Do any particular kinds of animals frighten or annoy you?
- » Do you like to be part of a group and participate in activities with people you know? If so, what kinds of activities do you most like to share? Some examples are travel, community service, sports (watching or playing), avocations like music or gardening, cooking, or any other leisure-time pursuit.
- » Do you like the idea of being in a group of people you don't know? Would you enjoy meeting people from different backgrounds? Or do you prefer to be around people whose backgrounds are like yours?
- » Do you find the idea of group activities unappealing? If so, what aspects do you dislike?
- » Do you prefer to do things on your own or with one or two people?
- » If you are a loner rather than a group person, would you find it hard to adjust to group living, even if you had your own living space?

- » Do you like to do things on your own rather than rely on others for help?
- » Even if you ask for help, do you like to oversee the details?
- » Do you have a cooperative nature — that is, do you like to work out problems with other people, or would you prefer to take charge or have someone else take charge of the solution?
- » Do you value stability and security above the possibility of change, even if it improves your life?

Attitudes about money

Now I come to the most sensitive part of the inventory. (I haven't included sex, but you can add that to your list if you like.) It's money — not just how much you have but how you think about it. Here too the goal is not to make a judgment about your financial-management skills but to provide a way to think about how you'll approach your future. In nearly every case, future care does involve spending money, and much of it will be from your own or your family's resources.

Do you have a philosophy about money? People say things like “Money is meant to be spent,” “A penny saved is a penny earned” (maybe updated to be a dollar), “It's important to save for a rainy day,” and “I'm spending my children's inheritances.” Sometimes, of course, these are offhand remarks, but even so they may indicate overall attitudes about money.

Even without an explicit philosophy, many people approach financial decisions within some basic framework of optimism, fatalism, or risk avoidance. Sometimes this philosophy has developed because of childhood experiences of poverty or difficult times in young adulthood, or the reverse, a lifetime of financial ease or a lack of responsibility. Different people react to financial stress in different ways. Think about your personal financial philosophy as you answer the following questions:

- » Do you know how much money is in your checking account, savings account, investment portfolio, pension fund, and other assets? Or do you leave that to someone else to manage?

- » Do you carry a lot of cash, or do you use credit cards for most purchases?
- » Do you buy a lot of products online or from television advertisers?
- » Have you ever regretted a major purchase bought on impulse?
- » Do you like to shop?
- » Are you or have you been in serious debt?
- » Do you know much money you are receiving (or will receive) from Social Security or a pension?
- » Do you know how much money your home (if you own it) is worth in today's market?
- » Do you know how much you pay in taxes and maintenance?
- » Do you have a regular household budget? Do you live within it?
- » How often do you get a new car?
- » Are vacations or travel an important part of your life?
- » Do you have current or future financial obligations to other family members, such as your grandchildren's education?
- » Would you be able to maintain these obligations if you were to start spending more on your own care?
- » Do you want to be able to leave money to children, grandchildren, or other people?
- » Do you want to be able to leave money to cultural, religious, or other institutions that you have supported?



TIP

A financial adviser can help you work out just what your assets are worth (you may be surprised to find you are worth more than you think) and create different options for accessing and spending this money. Different housing options have different cost profiles. Setting up a budget based on the costs that different housing options will require is a good way to determine what extra money you may have or how much you may need to trim from your current budget.



REMEMBER

To accommodate a lifestyle you prefer, you may have to start now to set priorities and limits. You should be comfortable with the financial plan as a basis for determining how much you can spend on future care without jeopardizing other important factors in your life.

Creating a Plan Based on Your Profile

The personal profile you have sketched in the preceding section, along with other items that are important to you, can offer guidance as you move forward.

For example, someone who belongs to several social and community groups, likes to meet new people, has generally good health, has no dependents (other than, perhaps, a spouse), and has sufficient financial resources to set aside for care may well consider assisted living. The facility may be nearby or in a setting closer to adult children or siblings (who, in this scenario, are financially independent). Check out Chapter 5 for more information on assisted living.

A person with a similar profile may not like group living and would prefer to spend the money on home modifications and home care assistance if necessary.

On the other hand, someone who already needs help with chronic health conditions, is struggling economically, and doesn't have many contacts outside family may find a multigenerational living arrangement worthwhile. In this scenario, the rest of the family can benefit as well from the contributions. This option can also involve a nearby setting or a move, depending on where family members live and who moves in with whom. It may even involve the creation of a new home to match the new household's needs.

For someone who suffers from serious health conditions and may need more care in the future, the options are more limited. More family or paid assistance will be required, either at home or in a skilled nursing facility (SNF). Home- and community-based services can provide a basis for the needed care, but if 24-hour care or care requiring special expertise is needed, these services won't suffice. A skilled nursing facility (or the extended-care section of a continuing-care retirement community) may be the most appropriate option (see Chapter 10).



REMEMBER

Between these two extremes, of course, lie many possibilities and options. But in evaluating specific settings and services, keep the personal inventory in mind as the framework for decision making. Someone else's decision may be perfect for that person. You want to make a decision that is right for you.

IN THIS CHAPTER

- » Remaining in your home in your community
- » Preventing falls and burns
- » Making a home safe and accessible
- » Lining up people to help in the home

Chapter 3

Fond of the Familiar: Staying in Your Home

Studies show that most people want to stay in their current homes as they age. But modifications may be necessary to accommodate changing needs, and you may need people and services to help with many tasks that you are no longer able or willing to do.

In this chapter, I guide you through some of the options available for home modification and obtaining outside help. I also review plans you should have in place to prepare the house and your family for a disaster such as a hurricane or flood or a more common event such as a power outage.

Staying at Home in Your Community

The common desire to stay in the same home is often called “aging in place.” This is a term most often used by professionals and policymakers, although not by older adults themselves. It may be misunderstood as being unable to leave your home or having other negative implications. When people say they want to stay at home, they often are thinking not only of their physical home but also their familiar surroundings.

When you think of staying in your home, think, too, of your community. In fact, the federal Centers for Disease Control and Prevention (CDC) has a broad and complicated definition of aging in place: “the ability to live in one’s own home and community safely, independently, and comfortably, regardless of age, income, or ability level.” This definition adds conditions to the circumstances under which aging in place should occur. The person has to meet all three conditions: be safe, comfortable, and able to live independently. Living independently may mean living alone without any outside help, or it may mean living alone only if outside help is available. The critical element is being able to choose what you do and when you do it.

Sometimes these conditions conflict. The home may be quite comfortable but not safe. Or the home may be safe, but only with help. Or all those conditions may be met, but you don’t have enough income or assets to support the arrangement.

The CDC’s definition also includes living in your community. This adds another layer of complexity. What exactly is a community? What if the home is safe but the neighborhood is not? What if the person doesn’t have a community of people nearby who can help as needed? Living alone shouldn’t mean living in isolation. What seems to be a straightforward definition turns out to be complicated. You can do a lot to make sure all these elements are in place, but some things are beyond any individual’s control.

Dealing with Two Major Hazards

An important first step in deciding whether staying in the same home can work is taking a hard look at the home. Looking past a cherished home’s attractive features and focusing on its flaws and hazards can be hard to do. Having someone with fresh eyes with you as you survey the premises can be helpful, preferably someone with experience in home modification for older people, such as a physical or occupational therapist, a geriatric care manager, or a contractor who has done similar jobs.



REMEMBER

If you’re trying to improve the home for a relative, be aware that older people often downplay concerns about safety and resist change. Be tactful but firm. Safety is not the only issue, but it is a prerequisite for enjoying a good quality of life.

Falls and burns aren't the only sources of injury at home, but if you address them, you'll likely prevent other kinds of injury.

Preventing falls

Your first priority should be preventing falls. Falls are among the most common accidents in homes. Older people are at risk for falls because keeping your balance as you age is more difficult, and it's harder to readjust your feet to regain your balance if you slip. Arthritis can limit your range of motion. Many older people suffer bone loss, or osteoporosis. Hips are the most likely joints to be injured because people tend to fall on their sides.

Falls are often the first step in a cascade of decline that ends up with a hospital stay and eventual placement in a nursing home or death. Fortunately, many fall-prevention measures are easy to take and are not expensive.

Here's a checklist for falls prevention adapted from the National Center for Injury Prevention and Control, a division of the CDC. The full list is available at www.cdc.gov/steady/pdf/check_for_safety_brochure-a.pdf. Another valuable CDC resource for family caregivers is available at www.cdc.gov/aging/caregiving/.

» Floors:

- When you walk through a room, do you have to walk around furniture? If so, make a clear path by moving the furniture.
- Are there throw rugs on the floor? If so, remove them or use double-sided tape or a nonslip backing.
- Are there papers, books, towels, shoes, magazines, boxes, or blankets on the floor? Pick them up and keep them off the floor.
- Do you have to walk over or around wires or cords (like lamp, charger, or extension cords)? Coil or tape cords and wires next to the wall. You may need an electrician to put in another outlet.

» Stairs and steps:

- Are shoes, papers, or other objects on the stairs? Remove them.
- Are some steps broken or uneven? Have them repaired.
- Does the stairway have a light? An electrician should install an overhead light and light switch at the top and bottom of the stairs. (Use an energy-saving light bulb so it doesn't need to be changed as often.)
- If there's carpet on the stairs, make sure it's firmly attached to every step.
- Make sure that handrails are not loose or broken and that they're on both sides of the stairs.
- To make seeing the stairs easier, paint a contrasting color on the top edge of all the steps. For example, use a light color paint on dark wood.

» Kitchen:

- Are often-used items on high shelves? Move them to lower shelves (about waist level).
- Is your step stool unsteady? If you must use a step stool, get one with a bar for support. Never use a chair as a step stool.

» Bathroom:

- Tubs and shower floors are often slippery. Put a nonslip rubber mat or self-stick strips on the floor.
- Install grab bars inside the tub and next to the toilet. Make sure you have this done by someone who knows how to place them correctly and securely. The screws should be installed in the studs in the wall, not in the tiles, or the grab bar will pull loose.

» Bedroom:

- Is the light near the bed hard to reach? Make sure a sturdy lamp is close to the bed.
- Is the path from the bed to the bathroom dark? Put in a night-light, preferably one that turns itself on after dark.

Preventing burns

Burns are a common problem in the home. Even a minor burn can lead to infection and serious consequences. Older people literally have thinner skin that's more susceptible to scalding from hot water or burns from electrical appliances. To keep older people safe from burns at home, make sure you

- » Replace electrical cords that are broken or cracked.
- » Replace electronic devices, heaters, or appliances that overheat, spark, or smoke.
- » Use a power strip rather than an extension cord.
- » Keep electrical appliances away from water.
- » Unplug small appliances such as toaster ovens and coffee-pots when not in use.
- » Keep a three-foot zone of safety around the stove, oven, and microwave.
- » Use microwave-safe cookware.
- » Set the water temperature to a maximum of 120 degrees Fahrenheit (this may be a job for a plumber or apartment building staff).
- » Use a humidifier that sprays cool mist rather than hot steam.
- » Have smoke alarms installed and change the batteries twice a year. You can use changes to and from daylight saving time as your reminder.



WARNING

Smoking in bed is still a common cause of fires. Do everything you can to prevent this dangerous habit.

A comprehensive brochure with guidelines for preventing burns from the Hearst Burn Center at New York Presbyterian Hospital is available at nyp.org/pdf/burn_center/Burn_Safety_Prevention_Older_Adults_englishWEB.pdf.

Modifying a Home

When you've completed your safety checklist and made all the easy fixes and repairs, you may find that problem areas still exist. Some may be unsafe conditions, but others may be barriers that

make it difficult for you to move about freely and to enjoy the comforts of home that make you want to stay put in the first place. This section covers modifications that can be made to an aging person's current home to allow for the present living arrangement.



TIP

For more information on this topic, check out the AARP Home-Fit Guide Downloads, Worksheets, and Resources at www.aarp.org/livable-communities/info-2014/home-fit-resources-worksheets.html.

Categorizing types of home modifications

Many houses and apartment buildings were constructed before universal design features were common or in some cases required by guidelines for remodeling and new construction under the Americans with Disabilities Act (ADA), passed in 1990. Ramps in public places, doors marked for wheelchair entrance, and buses with lifts and special seating for people with disabilities have become so common that they are scarcely noticed (unless of course you have a disability and need these accommodations). Yet the need for similar accommodations in private homes is less visible although equally important.

The Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) puts home modifications into three categories:

- » **Accessibility:** Accessibility modifications allow a person in a wheelchair or with disabilities to move easily throughout a structure, such as with widened doorways, lowered counter-tops and sinks, grab bars in the tub or shower, and light switches and electrical outlets at waist height.
- » **Adaptability:** Adaptability covers changes that can be made more quickly, without having to completely redesign the home or use different materials for essential fixtures.
- » **Universal design:** These features are usually built into a home, including appliances, floor plans, and fixtures that are flexible, sturdy, reliable, and easy for all people to use. A guide to universal design can be found at universaldesign.ie/What-is-Universal-Design/The-7-Principles/7-Principals.pdf.

These categories are important because they involve different levels of planning, implementation, and cost. For example, adapting a home is the least complicated type of modification. Grab bars and outdoor ramps are examples. Making a home accessible, however, may involve structural changes and complying with building code and ADA requirements. Universal design may come into play when you are completely remodeling a home or building a new space.

Checking out accessibility

General home safety issues (see the earlier section “Dealing with Two Major Hazards”) are important for all older people living on their own. But other specific features can make the home easy to use — or not — for people who have disabilities or are aging. Start in the kitchen and bathroom and think about the particular problems you may face in accessibility:

- » Are cabinet knobs or pulls easy to use? Pulls are generally considered easier to use than knobs.
- » Are stove controls easy to use and clearly marked?
- » Are faucets easy to use? Universal design faucets have one lever, not two knobs to turn. This makes mixing hot and cold water easier.
- » Can the oven and refrigerator doors be opened easily? Is the freezer easy to reach?
- » Is the kitchen counter height and depth convenient? Most kitchen counters are too high for a person in a wheelchair.
- » Is there room to move around the bathroom and a place to put towels and shampoo in easy reach?
- » Is the shower faucet easy to use? Turning on the shower and getting the right temperature can be difficult. A new showerhead or faucets may be needed.
- » Does the height of the toilet seat make getting up difficult? A raised seat may help.

In closets and storage spaces, check the following:

- » Does the closet contain items that have been put there to get them out of sight? Move them so the closet is easier to access for coats, hats, umbrellas, and boots.

- » Can items in the closet, like a coat on a hanger, be removed and replaced easily?
- » Can the use of storage space be improved with closet shelf systems?

Doors and windows may need the following updates:

- » Are the doors wide enough to accommodate a walker or wheelchair? The standard for a wheelchair is 36 inches. Most door openings are narrower.
- » Are the doors and windows easy to open and close?
- » Are the door locks sturdy and easy to operate?

Evaluate the electrical outlets and safety devices:

- » Are electrical outlets easy to reach?
- » Is the area around outlets free of clutter?
- » Are the outlets properly grounded to prevent shock?
- » Can you hear the doorbell in every room?
- » Is the telephone readily available for emergencies? A land line may be more reliable in an emergency than a cellphone.
- » Is there an alarm system? If so, is it easy to use? If not, consider whether one is needed.



TIP

The preceding information is only a partial list. The University of Southern California Leonard Davis School of Gerontology has an extensive resource list at <https://homemods.org/resources/>. Also see the 2020 AARP HomeFit Guide to help you plan when you remodel at www.aarp.org/livable-communities/housing/info-2020/homefit-guide.html. The guide has sections for each area of the home and outdoor spaces as well.

Some items that need correcting can be done by you or a friend or family member, but if you have determined that major changes are necessary — for example, widening doorways or replacing kitchen cabinets or appliances — you probably need to find a contractor to tackle the modifications. Head to the next section for advice on finding the right person for the job.



TIP

Remodeling is a messy and often frustrating experience. The first phase, demolition — even if it's limited to one room or area — is unsettling. Delays are common. It may be a good idea to move to another setting while the work is being done, especially if you expect a lot of dust, noise, and disruption.

Finding a contractor

How do you find a reliable and knowledgeable contractor? If you have already worked with a contractor and were pleased with the results, then you have a head start. Ask this person to go over the problem areas with you, suggest fixes, estimate the cost, and tell you how long it will take to do the work.



TIP

Most people with accessible homes have neither built their own houses nor undergone extensive remodeling. Ask for recommendations from friends or neighbors who have had similar work done. Check online referral sites for recommendations. Then ask a few contractors for estimates and for people to call for references. Some home builders work with certified aging-in-place specialists, a program developed in partnership with AARP. Visit www.aarp.org/livable-communities/info-2014/7-steps-to-hiring-a-contractor.html for worksheets and more information.

Before hiring a contractor, check with the local Chamber of Commerce or other agency to see whether any complaints have been filed against the company. Make sure the contractor is licensed to perform the work and can obtain any building permits required. Finally, ask for a written agreement that stipulates a small down payment and schedule of payments, with the final payment to be made only when the work is completed and approved.



WARNING

A frequent scam carried out against older people occurs when a “contractor” scans a neighborhood for a likely target and offers to do needed (or unneeded) repairs or home modifications. The person asks for a large down payment and either disappears or does only a token amount of work. If you're thinking of doing any home modifications, be on the lookout for this scam. Ask if you can contact other clients to find out if they were happy with the contractor's work. If the contractor brushes off your request, decline to work with them.



WARNING

Attempting any major repairs, especially if they involve climbing ladders or using power tools, is dangerous. Some people want to save a few bucks by doing the jobs themselves, but they need to be reminded that the cost upfront is much less than the aftereffects of being injured.



REMEMBER

If you live in an apartment building or housing complex, you need to contact the management to make some changes, particularly in corridors and stairways and even within the apartment itself. Co-op or condo residents may be required to obtain approval from their governing board too.

Getting help paying for home modifications



TIP

Many home modifications, such as ramps and lighting replacements, are relatively inexpensive. But when you start widening doors and installing new kitchen equipment like a refrigerator with side-by-side doors, the costs add up. In the bathroom, installing a roll-in shower can be costly although important for someone who cannot move from wheelchair to tub. Eldercare Locator, a federal agency funded by the Administration for Aging (AoA), suggests these resources for financial assistance:

- » Some funds for home repair may be available through Title III of the Older Americans Act. They are distributed through the local Area Agency on Aging (AAA). You can find your nearest AAA by calling Eldercare Locator at 800-677-1116 or going online at <https://eldercare.acl.gov/Public/Index.aspx>. These funds are likely to be limited, however, and best suited for relatively small jobs.
- » Rebuilding Together, Inc., a national volunteer organization dedicated to assisting low-income seniors, may be able to direct you to a local affiliate. You can contact it at www.rebuildingtogether.org.
- » Some types of home modification — those determined to be medically necessary — may be covered by Medicaid (for eligible low-income people), depending on the state you live in. For example, a roll-in bathtub or shower for a person in a wheelchair may be covered. A doctor's order may be required, and some Medicaid programs limit eligibility to certain diagnoses or ages. Check with your state's Medicaid office for details.

- » If the home is mortgaged and has substantial equity, a home equity loan may be available from the bank. However, this loan will increase the mortgage payment.



REMEMBER

Whether major improvements and their associated costs will substantially improve your safety and quality of life is a personal decision. You may decide that aging in place is not really feasible after all and that a move to assisted living or another setting is the best choice (see Chapter 5). If you do decide to stay, going through the important process of evaluating the home and making those small changes that can prevent accidents will make it much safer.

Seeking Help at Home

Creating a safe and comfortable environment is only one factor in staying in your home. Many older adults need at least some help at home. Some people need a little assistance with transportation and shopping, for example, while others need a lot of help with personal care such as bathing and dressing. People with complex chronic conditions usually need help with managing medications, operating medical equipment, monitoring symptoms, and similar tasks. In the following sections, I help you consider whether family members can provide those important services or whether you need to consider hiring trained professionals.

Allocating tasks to family

At least 80 percent of assistance at home is provided by unpaid family members. A first step for providing help at home is to allocate tasks to family members and/or friends. Talk to them to find out who's available and willing to help and what limitations they have. If several cooperative family members are involved, the tasks can be divided. One person may be able to spend several afternoons a week shopping and preparing meals, while another can manage medications and doctor visits. A friend may be able to pick up prescriptions from the pharmacy or drive to religious services.



TIP

When you arrange a plan for allocated tasks, make (or have someone help you make) a master list of family helpers, their phone numbers, their tasks, and the schedule. Put the list in an easy-to-find place, such as on the refrigerator, to help the person being assisted remember who is coming when. Also be sure to distribute the list to family and helpers so everyone knows what tasks are being taken care of.

Searching for services

When family members and friends can't provide all the help that is needed, paid home health or companion services provided by agencies or hired privately can fill the gaps. One factor in your decision to stay in your home may be the availability — and affordability — of these services. Home care comes in many varieties and from many different sources.



REMEMBER

Medicare (Original Medicare and Medicare Advantage plans), Medicaid, private health insurance, and long-term care insurance have their own rules and criteria for providing services. Some people are covered by more than one policy. Here are a few key points to remember when working with insurance plans:

» Medicare home healthcare is intended to be part-time or intermittent (not constant). The goal, according to Medicare, “is to provide treatment for an illness or injury.” The Medicare home health benefit “pays for you to get certain healthcare services in your home if you meet certain eligibility criteria and if the services are considered reasonable and necessary for the treatment of your illness or injury.” See www.medicare.gov/coverage/home-health-services.html for more information.

To be eligible for this benefit, you must have a need for skilled nursing — that is, the kind of care provided by a nurse or physical therapist.

» Medicaid for low-income people provides long-term home healthcare, including aide services, but eligibility and availability vary by state. Many states have created Medicaid Managed Long-Term Care plans (MMLTC), which are implemented by private companies.

» Private employer-based insurance generally follows Medicare rules.

- » Home care services are generally available through long-term care insurance but vary by policy, and there may be waiting periods and other limitations.
- » Hiring workers privately is also an option that gives you more flexibility but also more responsibility.

Having reliable, competent, and friendly home care workers can make a big difference in someone's ability to age in place, but working out a suitable arrangement takes time and effort — and often money.

Finding help for other chores

In addition to family, friends, and paid home care workers, you may need additional help in taking care of pets, maintaining the yard, cleaning the gutters, and all the other chores that become difficult to do. If these regular maintenance tasks aren't taken care of regularly, the home can quickly deteriorate, leading to safety problems as well as expensive repairs. Serious problems, such as a leaking roof or frozen water pipes, can create havoc. Chores that involve climbing, shoveling, heavy lifting, and other strenuous activities are best done by someone younger and stronger.



TIP

Some community agencies and religious organizations have volunteers who will help with these chores. Ask the organizations you belong to or senior centers for suggestions. Local schools or universities may also have community service programs for students. Some heavy or risky chores should be performed only by trained workers. If you hire people to help, make sure that they give references and do the job competently.

Putting technology to use

Technology is all around us, and *assistive technology* — devices and adaptations that are designed to help people who are aging or have disabilities function independently — can make a big difference in a person's ability to stay at home safely. Assistive devices come in all sizes and shapes and can be cheap or very costly. Earlier in this chapter, I mention some common assistive devices — grab bars, handrails, and raised toilet seats. Other common devices are hand-friendly tools for opening jars or gardening, TV remote controls with big numbers, and Personal Emergency Response Systems (PERS), the kind immortalized and satirized in the TV commercial, "I've fallen, and I can't get up!" In the healthcare

world, telehealth — distance monitoring of chronic conditions like daily weight checks on a person with heart failure — is growing, especially in rural areas.

How far you're willing to go to bring assistive devices into your life is a personal choice. Inventors and investors have identified people staying at home as a huge market for these products. The products include mattresses that sense every movement and can relay information about how many times the person gets up to go to the bathroom or the kitchen, monitors that track a person's movements in the home, and GPS devices that can locate a person with dementia if she wanders.

Buying an assistive device is only the first step. You have to learn how to use it and perhaps teach an older adult or an aide how to use it. Some devices that seem simple are not. For example, a cane is probably the most common assistive device. Yet it should be the right length and used on the correct side of the body. (*Hint:* It's not the side where the pain or injury is.) And as you move up the scale toward devices with moving parts and controls to set, the need increases for adequate instruction and someone to call when there are problems. Constant monitoring means constant responses, most of which will turn out to be false alarms. If you're the responder, it can become all too easy to ignore that flashing red light or annoying beep.

Looking for technological solutions to the problems of aging overlooks a basic human need for contact with other people. And while technological devices offer to provide peace of mind, the devices themselves can fail and at best require someone to respond whether there is a real emergency or just a faulty sensor. That in itself can be a major responsibility.

IN THIS CHAPTER

- » Understanding downsizing's emotional aspects
- » Making downsizing part of home adaptations
- » Taking the first step
- » Going ahead with a move

Chapter 4

Downsizing for Now and Later

Every day brings a new deluge of ads for consumer goods — by mail, newspapers, and magazines, and through messages on our computers, tablets, and cellphones. America has been called, with good reason, a consumerist society.

But there is another trend that emphasizes a minimalist style of living, with fewer material possessions and accumulations from the past. The examples range from books and websites that stress the joy of decluttering and the ease of living in “tiny” homes (really tiny, as in 100 to 400 square feet) to its ultimate expression in the Swedish practice of “death cleaning” — ridding yourself of your belongings while you’re alive.

Is there a middle ground? This chapter is designed to help you find it for yourself. *Downsizing* is the term most often applied to this process, but I think of it as *rightsizing*, a term borrowed from the business world, sometimes to justify getting rid of jobs and therefore employees. In this case it’s just getting rid of things.



REMEMBER

You may or may not be thinking of a move. If you are, then downsizing is not only appropriate, it is essential and best addressed as early as possible. If a move does seem probable, give yourself six months to a year to plan and to do the job carefully and without undue stress. But even if a move isn’t in your immediate plans,

downsizing can make your home safer, more comfortable, and more welcoming. The goal of downsizing is to find the right balance between your desire to keep your belongings and memories and your need to have a comfortable, safe, and decluttered home. Whether you move now or later, you'll have already done the hard work of choosing what matters most to take with you.

The Emotional Aspects of Downsizing

Most of the work of downsizing involves sorting, organizing, decision making, and disposing of the things you no longer need or want. Hard enough, but unless you recognize the emotional toll this process can take, it will be even more difficult. It's not just the items with obvious personal history such as wedding photos or grandparents' silverware; it's often ordinary items that bring back memories of childhood or places that you visited. Allow some time to reflect on these memories before deciding whether the items they are attached to stay or go.

Some people attach emotional value to items that represent unfulfilled goals. The sewing machine reminds Mom of the projects that she never got started and Dad the expensive woodworking tools that he can never figure out how to use. These lost opportunities may loom larger than items that are attached to completed projects.

People who experienced hard financial times may collect things that once were hard to come by but have no real use now, such as monogrammed towels or heavy suitcases. The personal profile in Chapter 2 may help you determine what characteristics define your personality, including your attitudes about money. These may play a role in downsizing.

While you're going through items, think about who in your family would want them. If there is conflict about distribution, it may be time for a family meeting led by a trusted friend or professional.

The positive side to downsizing can't be overlooked. In the newly streamlined space, you can reposition furniture, highlight items you value highly, and in general make an old space both familiar and new. And there's the practical benefit of making it easier to

clean and to find things that always seem to be missing — your glasses or keys, for example.



TIP

In the award-winning AARP's *Downsizing the Family Home* (Sterling), home and lifestyle columnist Marni Jameson offers helpful advice on both the practical aspects of downsizing and the emotional impact of the process. She and her brother managed their parents' move from a family home laden with 50 years of memories to an assisted-living apartment. Her expertise and experience can be useful for someone planning to stay or move.



TIP

One way to keep memories alive is to take photos of objects that you don't want to keep but don't want to lose altogether. The photos can be put into digital form and shared with family and friends.

Downsizing and Home Renovations

A good time to think about downsizing is when you're considering renovating your home to make it more accessible (see Chapter 3). Look at the spaces you're considering adapting: the bathroom, kitchen, or stairs, for example. Removing hazards and opening areas for easy access can be the first salvo in the downsizing effort.



REMEMBER

Don't just toss the removed items in another area where they may cause new problems. Take stock of what's been removed and what can be disposed of right away and what you want to save or give away. Chances are items have accumulated in these spots because the locations are convenient, not because the items have a purpose there. Combining decluttering with a process that improves the living space may defuse the emotional response.

Getting Started

Where to start downsizing? The following sections describe a few important steps.



TIP

If adult children still use your home or garage as a storage facility for their belongings, ask them to help your downsizing project by removing their possessions. Explain that you're working to streamline your home to make it safer and more accessible, and that their belongings should live with them. When they see how difficult it can be to make decisions about their school papers and other memorabilia, they may be more tolerant of your own challenges in downsizing.

Putting together important papers

A good first step in downsizing is looking for the important papers that you'll need to keep and those that can be discarded. Among the critical papers to keep are deeds, mortgage statements, birth and marriage certificates, tax records, passports (check to see whether they are still valid), diplomas, and military service records. Keep all these together in a safe place and let family members know where they are.

Assemble legal papers that are important right now (or can become important in a medical emergency). These include advance directives, including those naming healthcare proxies, do not resuscitate (DNR) orders, durable power of financial attorney, a will, a list of current medications, and other medical records (see Chapters 8 and 11 for more information on these documents). These should be kept in a safe place as well, but should be readily available in an emergency. AARP's *Checklist For My Family* by Sally Hurme (American Bar Association) offers lists of what to keep and for how long.



TIP

Check with your accountant or tax attorney to find out how long you should keep tax records. There are different rules for different situations, and you want to be sure you can discard (shredding is advised) some old records.

Sorting and decision making

After you've gone through the important paperwork and the kids have taken their things, don't stop the momentum. It's time to sort through the bigger stuff.



TIP

The Family Caregiver Alliance's checklist for caregivers on downsizing a home (www.caregiver.org/downsizing-home-checklist-caregivers) recommends four categories, each designated by a colored tag or sticker. In this scheme, green = save, orange = possibly save, blue = donate/sell, and red = discard. You can label boxes and

garbage bags with the different colors. The goal is to begin to determine where different items will be going. Don't make the mistake of tagging everything green for save; that defeats the purpose. And if there are no red tags for discard, you aren't facing reality.

Start small. Pick one area — a drawer or closet, perhaps, or a seldom-used bedroom. This technique puts some boundaries around your tasks and reduces feelings of being overwhelmed. You may find things you've forgotten existed and some you swear you've never seen before. If you've gotten along without them until now, don't put them in the "save" pile!

When you've done all you can do in your small designated area, make sure you immediately get rid of all the items tagged or boxed for discarding. The temptation to move things from red to orange or even green can be very strong. If something should be discarded, discard it as soon as possible. Out of sight, out of mind. If the items are big, you may need to arrange a special trash pickup. If something is going to be donated, donate it immediately. (See the next section.)

Continue going through your house room by room, or closet by closet and file cabinet by file cabinet. As you move through different areas and rooms repeating this process, you may come across items you want to give to particular individuals. You can do this in two ways: Give the person the object now with an explanation of why you think it would be meaningful to him or add the designation to your will so the person will get it later. Many wills just set out a process for determining how family items are divided so it is as fair as possible.

Consider how other people may react to this gift and whether other items you find will be appropriate for them. You should be prepared for the possibility that the friend or relative you have carefully chosen to receive an item you consider precious won't want it.

Donating or selling items

You may be surprised to find that sometimes it's hard to donate and even harder to sell things. If you have artwork, first edition (or rare) books, or expensive jewelry that you don't wear anymore, your first step is to have these items appraised by a knowledgeable dealer. You can also look on the Internet for auction or sale prices for comparable pieces.

But be prepared. The artist whose works you bought 30 years ago may have become famous . . . or faded into obscurity. Or maybe it's the frame that's valuable, not the artwork. Your great-grandfather's collection of campaign buttons may be valuable or not. Your father's toy train set may bring a handsome price (especially if you have the original box), or it may just be another example of a mass-produced product. Upright and console pianos, once prized possessions in middle-class homes, are hard to get rid of now. If you have a piano in reasonably good condition, or one that can be brought back from disuse, ask a piano tuner for schools or organizations that may be able to use it.

If you donate the items, you need the value for your tax return. You can find an Internet site that values items. And if you're going to try to sell them, you need the value to set a fair price or a price that you will accept.



TIP

In the happy event you turn up something with considerable value and you decide to keep it, you should add it to your homeowner's insurance policy.



TIP

Check with local service agencies, such as the Red Cross, the Salvation Army, homeless shelters, and others, to find out whether they accept donations of household items and, if so, what kinds. They may have specific requirements and may pick up the items. They may take kitchen utensils, for example, but not bedding. Libraries may take books in good condition for book sales, or they may not. Donating items to a service organization that you support is a good way to show the group that you value their contribution to the community. They will appreciate your gesture, and you will feel good about the donation.

You can try to sell items that you don't need in your newly streamlined home, including furniture and tools, individually on a website such as eBay or Craigslist, with the understanding that you may have to deal with many responses that don't result in a sale. Or you can give some of them to a consignment shop that displays and sells the items for a percentage of the sale price. Or you can hire an estate sale company, even though this is not, strictly speaking, an estate sale.

Another option is a yard or garage sale, if someone in the family has the time and energy to organize it. Don't underestimate the time it takes to organize a sale. You have to examine each item,

decide on a price, label everything (even those things you don't want to sell to make sure no one walks away with them!), place them strategically, advertise the sale, and then have someone to handle sales and another person to monitor the crowd.

Making the Move

You may have started the downsizing process with every intention of staying in the same home, but perhaps over time it has become clear that it's time to move. But working with a moving company presents its own challenges.

Moving companies are regulated by states; this website will take you to your state's rules: www.relocation.com/library/moving_guide/state_regulations.html. If you're moving to a different state, federal rules are described in the Department of Transportation's Federal Motor Carrier Safety Administration website at <https://www.fmcsa.dot.gov/protect-your-move>. You can also check the Better Business Bureau and, of course, the reviews on consumer websites.

Whatever company you choose, keep in mind this advice from the Family Caregiver Alliance's fact sheet at <https://www.caregiver.org/downsizing-home-checklist-caregivers>:

- » Be sure you have a written contract from the moving company and a clear idea of coverage for lost or damaged possessions.
- » Get a firm time for their arrival, at both the old and new residences.
- » Check inventory lists.
- » Check payment options: credit card or check?
- » Have someone assigned to meet the movers at the new residence. Be sure they have a key! If this is a facility, be sure the manager is expecting you.
- » Ensure that all boxes are properly labeled.
- » Use the "open first" boxes to set up the bedroom and bathroom immediately.
- » Prepare to spend a few days unpacking and organizing. Get someone to help if you can. Work as quickly as you can to make this new home feel homelike.

- » Defining assisted and independent living
- » Asking questions about services and costs
- » Exploring other options for group living

Chapter 5

Assisted and Independent Living and Other Group Settings

It's a common problem: Your house is too big and costly to maintain. Or your kids live across the country and you want to live closer to them and your grandkids. But no one wants to give up privacy and independence. Whatever your situation, assisted living may seem like a good solution. And the ads stress how pleasant and easy life can be in a place called, say, Gracious Living Manor. But you have a lot to think about before taking such a big step.

When choosing whether assisted living is the way to go for your situation, there are many considerations. This chapter guides you through all that comes with assisted living: the services, options, costs, and more. I also cover alternative group-living arrangements. But first, it helps to know exactly what assisted living is, so read on.



REMEMBER

You are looking for a home, not a hotel or a temporary place to stay. Whether the ultimate choice is assisted living or some other group arrangement, or to age in place, it should be a decision that is based on your needs, preferences, and resources.

What Is Assisted Living?

Assisted living is a term that is often used as though everyone understands it in the same way. But that's not the case. Assisted living is just a generic term like *hotel* or *automobile* that covers a lot of options. Before getting into the specifics, I like to start with a simple definition: Assisted living is a residence where groups of people share meals and other activities and where individuals can receive personal assistance to maintain their independence. People who choose assisted living typically would have difficulty living completely on their own but do not require constant medical attention.

You can also think about assisted living as an intermediate step in long-term care. It's in the middle of the spectrum of long-term care, which often goes from independent living to assisted living to nursing-home care. Independent living can be in your own home or the entry level of assisted living or in special housing for older people. About 70 percent of residents in assisted living come to the facility from their own house or apartment.

In this section I cover other terms for assisted living, what services are included, which healthcare options may be provided, and tips for finding a facility to provide a broader understanding of all that assisted living covers.

Knowing other terms for “assisted living”

State governments, which license group residences, call assisted-living facilities by different names. Some examples of state licensing categories are *residential care facilities for the elderly* (California), *residential facilities for groups* (Nevada), and *personal care homes and assisted-living facilities* (Pennsylvania).



TIP

You may come across the acronym *ALF* in your search. It is shorthand for assisted-living facility, not the character in the TV series popular in the 1980s. Similarly, *ALP* is an abbreviation for assisted-living program, not a mountain.

Owners of assisted-living facilities tend to shy away from that term in the name, preferring more appealing names like *village*, *community*, *manor*, or any phrase that evokes a secure and invigorating lifestyle.



REMEMBER

Your state's name for assisted living is not as important as its licensing requirements and its monitoring activities. Some states have detailed standards about what counts as assisted living and what must be provided, as well as building and safety regulations. States may require training for staff, background criminal checks, and other safeguards. Regulations in other states are less definitive. The National Center for Assisted Living, a provider organization, has information about state offices at www.ahcancal.org/ncal/about/Pages/StateAffiliates.aspx and a state regulatory review at www.ahcancal.org/ncal/advocacy/regs/Documents/2017_reg_review.pdf. Another important publication is the National Center for Assisted Living's "Guiding Principles for Assisted Living" at www.ahcancal.org/ncal/about/Documents/GPAssistedLiving.pdf. This guide offers a good check on the kinds of information that providers should be giving you as a prospective resident, including contracts, finances, and resident transfers.



TIP

When you check out your state's regulations, find out whether it has a bill of rights for assisted-living residents. Most states have such a document and generally require facilities to post it and give copies to residents. These documents may be lengthy. Some of the items include the right to privacy, to confidentiality of personal and medical information, to have private communications with a physician or attorney, to practice the religion of one's choice, and to be given notice about transfers or fee increases. Some are negative rights, such as the right not to be coerced or required to perform work. However, not all the documents tell residents how to complain if they feel their rights have been violated. One way is to contact the state's long-term care ombudsman, who is responsible for investigating complaints in nursing homes and assisted-care facilities. You can find the ombudsman in your area at www.litcombudsman.org/ombudsman. Or you can contact the National Consumer Voice for Quality Long-Term Care at www.theconsumervoice.org.

Getting to know what assisted living offers



REMEMBER

All assisted-living facilities, however defined, offer three main components:

- » **Shelter:** Residents are given a place to live, usually a private unit or apartment.

- » **Meals:** Food is provided, although not necessarily three meals a day.
- » **Staff:** The facility staff provide the assistance that comes with the name. In addition to managers and activity directors, most facilities have aides or attendants to help with bathing, dressing, getting around with a cane or walker, and other daily tasks.



TIP

When it comes to services provided by staff, you may frequently hear the term *ADLs*. It stands for *activities of daily living*, which are the actions people take for granted until they can't do them by themselves anymore — dressing, bathing, going to the bathroom, and feeding themselves. *ADLs* have a companion term — *IADLs*, or *instrumental activities of daily living* — that includes tasks like making phone calls, managing money, managing medications, shopping, and cooking. People in assisted living may also need help with these responsibilities.

Assisted-living facilities may be located in cities and look like ordinary apartment buildings. Some are in suburban locations with lots of open space. There are fewer assisted-living sites in rural areas.

Some assisted-living facilities are luxurious and provide a wide range of services and amenities. At the other end of the spectrum, some facilities have small staffs and offer limited assistance.



REMEMBER

When you're considering an assisted-living facility, be sure to ask about staffing: how many, training, special skills, and background checks. If the management seems evasive, probe further. The response will give you an idea of whether this is a place you want to consider further or avoid.

Assisted-living facilities may be large or small. About a third of all facilities are considered large (25 or more beds), but they have more than 80 percent of all assisted-living residents. About 82 percent of all facilities are run by for-profit organizations, some of which are national or regional chains. The rest are run by charitable or religious organizations or by state, city, or local governments.

In general, larger facilities have more staff and can offer more activities. This benefit may be offset by frequent staff changes and a more impersonal management style. Your preferences

about small-group living versus a large residence should be part of your decision. If you have always lived in a private house with few close neighbors, it may be difficult to adjust to large-group living, even if you have your own apartment. Or a new environment may be just what you are looking for.

Checking out healthcare services

The healthcare services offered in assisted living vary considerably. Most common is assistance with administering medications. Some states require staff with specialized training to help with this task. Some assisted-living facilities have medical staff, usually a nurse, available 24/7 on-site; others have a part-time nurse or someone on call.

Compared to practice 20 years ago, assisted-living facilities are now accepting people with more serious chronic conditions. The National Center for Health Statistics, a government agency, reported in 2010 that 82 percent of assisted-living facility residents had Alzheimer's disease or dementia, high blood pressure, heart disease, or a combination of those conditions. Some assisted-living facilities have adapted to the greater healthcare and assistance needs of these residents, while others have not.



REMEMBER

If you have a chronic condition that requires frequent monitoring and checkups, be sure to ask whether you can continue to see your own doctor or what alternatives will be available, especially if you're moving to a new area.



REMEMBER

Alzheimer's disease and other types of dementia are conditions that require specific care and are a huge factor when making a long-term plan. A 2012 MetLife Mature Market Institute survey of long-term care costs found that about half of assisted-living facilities provided Alzheimer's and dementia care, but 61 percent of them charged an additional fee. Sometimes the special units or programs within a facility are called *memory care*, perhaps to avoid the stigma of dementia. If memory care is important in your plan, be sure to ask about the staff qualifications and training, types of programs available, and opportunities for interaction with other residents. Also ask whether behavioral interventions are used instead of psychoactive drugs, which should generally be avoided. And care for people with dementia should be more than keeping them from wandering; it should include activities designed to stimulate their minds and keep them active.

Finding more information on assisted-living facilities

Your goal is finding the right assisted-living situation, one that offers the right balance of independence and privacy with the kinds of assistance you need now and may need later. After you know more about assisted living, you can begin your fact-finding process.



TIP

You can get information about specific assisted-living facilities from many sources. A lot of marketing information stresses the *living* aspect of assisted living and glosses over the *assisted* part. It's hard to find out how friendly the staff is, whether management is responsive to concerns, and all the other quality-of-life questions that matter so much. You have to ask about and observe these aspects for yourself. But you can learn a lot from some basic resources, including the following:

» **Eldercare Locator:** This federal resource (<https://eldercare.acl.gov/Public/Index.aspx>) is a good place to start. It directs you to your nearest Agency on Aging for assistance. There is also a basic introduction to assisted living at https://eldercare.acl.gov/Public/Resources/Factsheets/Assisted_Living.aspx.

» **State websites:** State websites are important because you can generally find which assisted-living facilities have a lot of health and safety violations or don't offer what you're looking for. You can then eliminate these from consideration. Some states also have good consumer information, specific to that state, on their Office of Aging or Health and Human Services websites. Note, though, that these agencies have different names in different states.

» **Your state's long-term care ombudsman:** This individual investigates complaints about assisted-living facilities and nursing homes. Check with that office, usually located in the State's Office on Aging, to find any complaints about a specific facility and how they've been addressed.

» **The Commission on Accreditation of Rehabilitation Facilities:** This nonprofit organization lists continuing-care retirement communities that meet its survey standards about business practices, philosophy and physical environment, and some aspects of assisted living. You can contact it at www.carf.org/ccrcListing.aspx.

- » **Argentum** (formerly the Assisted Living Federation of America): A membership organization of assisted-living providers, this group has a website at www.argentum.org/about-argentum/state-partners/ where you can search for its state partners.
- » **Internet sites:** When you search on the Internet for “assisted living,” you can find ads for specific facilities as well as companies that offer to help you find a facility in your area. Sometimes these companies are endorsed by celebrities, which isn’t a guarantee of quality. Personal assistance from “care” or “family” advisers may be available. Facilities on these lists typically pay to be included, so not all options may be offered to you.
- » **Friends or relatives:** People you know who are currently in or have lived in assisted-living facilities are a good resource for information on local facilities. Keep in mind, though, that one person’s good or bad experience may not convey the whole picture.
- » **Doctors and other healthcare professionals:** Talk to doctors and nurses with experience in providing care to assisted-living facility residents.



TIP

Use more than one resource, because no single one is likely to have all the options. Be aware of the criteria for including the assisted-living facilities and the sponsorship of the list. And none of these resources can tell you what it’s really like to live there. You should address questions about quality of life in your visits to various facilities. I suggest some specific questions in the later section “Beyond the Brochure: What to Look for When You Visit.”

Evaluating the Cost of Assisted Living



REMEMBER

Now the big question! How much does assisted living cost? No surprise, this question isn’t easy to answer. But it’s important, because you or your family will have to pay most of the costs of assisted living. There are two big costs to consider: the entry fee and monthly costs.

- » **Entry fee (sometimes called a community fee or security deposit):** Some but not all assisted living facilities require an upfront cost of admission. This cost varies considerably

across the country and by type of apartment or unit and other factors. Some fees may be a few thousand dollars; high-end facilities may have a starting point of \$100,000. Many people use the proceeds from the sale of their homes to finance the entry fee.

- » **Monthly fee:** Monthly fees fall into a range, but on average the cost of assisted living for a one-bedroom, single-occupancy unit currently is around \$3,750 a month, or \$45,000 a year. Genworth Financial, Inc., an insurance holding company, conducts an annual comprehensive survey of assisted-living costs. You can find information by state at www.genworth.com/about-us/industry-expertise/cost-of-care.html.



REMEMBER

Assisted living is largely private pay, meaning that you have to come up with the money on your own. You may be able to obtain some financial assistance, but for the most part, your own dollars will pay for assisted living. Some portion of the fees may be tax-deductible, so check with your accountant.

Choosing from the menu of cost plans

Stand-alone facilities typically have a selection of plans that are based on the type of services included. While the cheapest option may be attractive for many, the additional costs, particularly for added personal care, can become burdensome. Be realistic about what you may need. Keep in mind that additional services may be added when needed rather than being included upon entry to the facility.

If the assisted-living facility is part of a continuing-care retirement community (CCRC), which provides a wide range of living arrangements on one campus, then services and costs will probably be tiered. Generally, they fall into the following three categories. (A fourth model, which is essentially a rental agreement, may also be available.)

- » **Type A, extensive or life-care contracts:** This service plan provides housing, residential services, and amenities, including unlimited use of healthcare services, at little or no increase in monthly fees as a resident moves from independent living to assisted living to nursing-home care. The trade-off is usually a higher entry fee.

- » **Type B, modified contracts:** Often with lower monthly fees than Type A contracts, these plans include the same basic services, but only some healthcare services are included in the monthly fee. The resident pays for additional services beyond a minimum, perhaps at a discounted rate.
- » **Type C, fee-for-service or à la carte contracts:** These include the same basic services as Type A and B contracts but require residents to pay for all health-related services on an as-needed basis. These contracts may have lower entry and monthly fees for the independent living portion of the stay, but there is a risk of higher nursing-home expenses.

The higher the entry fee, the more likely it is that monthly charges will not increase. And the reverse is also true.

Which plan to choose depends partly on your current and foreseeable needs but also on your emotional and financial tolerance for risk. With Type A and Type C contracts, you get the same apartment and same basic services, but the difference will show up if — more likely, when — you need more assistance.

To get some idea how these options vary, Table 5-1 shows the range of fees by contract type for a selected group of continuing-care retirement communities.

TABLE 5-1 **Range of Fees by Contract Type for Continuing-Care Retirement Communities**

Fee	A: Life Care	B: Modified	C: Fee for Service	D: Rental
Entry fee/security deposit	\$160,000–\$600,000	\$80,000–\$750,000	\$100,000–\$500,000	\$1,800–\$30,000
Independent living monthly fee	\$2,500–\$5,400	\$1,500–\$2,500	\$1,300–\$4,300	\$900–\$2,700
Assisted living monthly fee	\$2,500–\$5,400	\$1,500–\$2,500	\$3,700–\$5,800	\$4,700–\$6,500
Nursing care monthly fee	\$2,500–\$5,400	\$1,500–\$2,500	\$8,100–\$10,000	\$8,100–\$10,700

Table source: U.S. Government Accountability Office, “Older Americans: Continuing Care Retirement Communities Can Provide Benefits, but Not Without Some Risk” (June 2010).



REMEMBER

Part of the entry fee may be refunded after you leave or die. This may vary by type of contract. Make sure it's spelled out in the contract.

Asking questions to create a monthly budget



REMEMBER

After you have narrowed your search to a few likely possibilities, you should ask for more specific costs. Here are some basic questions suggested by the National Center for Assisted Living:

- » What is included in the basic monthly cost? Ask for written information.
- » Does the residence have a written schedule of fees for extra services? If so, request a copy.
- » Under what circumstances may the fees change? How much notice is given for fee increases?
- » Is a security deposit and/or an entrance fee required? What is the refund policy?
- » Can service agreements and/or contracts be amended or modified?

With this information, you can create a budget for monthly costs that includes

- » Basic services, whatever model you choose
- » Potential additional services, such as
 - Personal laundry
 - Medication assistance
 - Entertainment and field trips
 - Transportation
 - Telephone
 - Cable television
 - Internet service
 - Beauty shop or barber
 - Special diets (if available)
 - Other charges

In coming up with a budget, be sure to consider what costs you'll no longer be paying (rent or mortgage, home insurance, snow removal, gardener, housekeeper) and what costs will simply be transferred to a new provider (Internet, cable television). Most meals will be provided (depending on the plan), but you may still want to eat at a restaurant occasionally.



REMEMBER

Keep in mind that costs are more likely to go up than down. This is especially true as more personal care and medical services become necessary.

Beyond the Brochure: What to Look for When You Visit

Of all the steps you can take in looking into assisted-living facilities, the most important is your visit. I should say your *visits*, because you should go more than once, both on planned visits and on unannounced drop-ins. An unplanned mealtime visit can give you essential information, not just about the food but also about the atmosphere in the dining room. Try to visit an activity to gauge the level of participation and enthusiasm. What you see, hear, taste, and smell can tell you more about how the facility actually runs than a whole folder of brochures, lists, and websites. Above all, talk to the residents. If the management discourages this, it's a bad sign.



REMEMBER

Ask as many questions as you can think of. But also trust your instincts. Is this a place you can see yourself living? Do you get a good feeling from the residents and the staff? Don't ignore small warning signs that may alert you to bigger problems. And don't be rushed into a quick decision.

The following sections walk you through what to look for when visiting an assisted-living facility, both in the common areas and in the individual residential units, as well as noting how a continuing-care concept works.

Making notes about the common areas

The staff member who takes you on a tour will be sure to point out the highlights of the furnishings, the dining room, the grounds (assuming the facility is not in the middle of a city), and all the

available amenities. These things are important, but also take a close look around the public areas to find the answers to the following questions:

- » Are they clean and litter-free?
- » Are the bathrooms clean and well stocked?
- » Do the walls look freshly painted?
- » Is there good natural light?
- » Is the temperature comfortable?
- » Are there comfortable seats for residents and visitors?
- » Are all the areas accessible for people with mobility problems?
- » Are there elevators?
- » Do you see residents with canes, walkers, and wheelchairs? If not, you may assume that none of the residents need this equipment, but it may be that people with disabilities stay in their rooms and don't feel welcome in the public areas.
- » Are exits clearly marked?
- » Can you eat when you want, or are mealtimes set?
- » Is there an easy give-and-take between staff and residents?
- » Do you feel welcome as a visitor?
- » If you are used to ethnic foods or have religious restrictions about foods, can the facility provide appropriate meals?

Checking out the residential units

You should also visit a typical apartment or unit. Make sure you see more than the model apartment, which may have special amenities that are not always part of the basic package. The residential unit is where you will spend a lot of time, so you want to be sure it is big enough and can accommodate the personal items you'll want to bring. Also find out the answers to these questions:

- » Is there a 24-hour emergency call system that is easy to use?
- » Is there space in the bathroom for someone to assist with bathing?
- » Is the kitchen (if there is one) well laid out and easy to use?

- » If there is no kitchen, is there a place to keep food?
- » Are the telephone and television easy to operate?



TIP

AARP has a good summary checklist of questions to ask when you visit and spaces to note the answers and your reactions. The checklist allows you to enter comments about more than one visit. You can find it at http://assets.aarp.org/external_sites/caregiving/checklists/checklist_assistedLiving.html.

Investigating continuing care

Assisted-living facilities may be stand-alone sites or may be affiliated with a hospital or nursing home or integrated healthcare system. Many assisted-living facilities are part of a continuum of care that starts with independent living and moves through assisted living to nursing-home care, called a continuing-care retirement community.



TIP

The CCRC promise of never having to leave to go to a separate nursing home temporarily (for a minor illness or accident) or permanently may seem like an attractive option. Many people, however, fail to investigate the nursing-home level of care as extensively as they do the entry level of independent or assisted living. The management may not be as eager to show you the nursing-home setting as the dining room or activity center, but ask to see it anyway. One thing to observe: Are there visitors from the assisted-living section? Sometimes people moved to the nursing home become isolated from their friends still in assisted living.

Independent Living and Other Options for Group Living

Perhaps you don't need the level of care provided at assisted-living facilities. Or perhaps the idea of living with a group of strangers, whose backgrounds may or may not be similar to yours, doesn't appeal to you. You would rather spend time with people who share some aspect of your history or experiences.

What options are there? You have a few, but finding the right one is often a challenge. The five main choices are independent living for seniors, affinity communities, cohousing arrangements,

house sharing, and group homes. In general, none of them have the same range of services as in most other assisted-living facilities, but exceptions exist. These alternative settings vary, depending a lot on the organization that started them.

Independent living for seniors

Independent living covers a wide range of options — including Naturally Occurring Retirement Communities (NORCs) and Villages. Most definitions of independent living include any housing arrangement designed or adapted for people aged 55 or over. Some are low-income or subsidized senior housing, and some are high-end retirement communities, complete with golf courses and other amenities. In a continuing-care retirement community, independent living is the first level. Whatever the arrangement, the emphasis is on providing a safe and barrier-free environment where basic services are provided to people who can manage with little or no assistance.

Affinity or niche communities

Affinity or *niche* communities are for people who have common backgrounds, usually because of prior employment. Special types of affinity communities also exist for lesbian, gay, bisexual, and transgender individuals (LGBT) and for military veterans. There are approximately 100 of these niche communities around the country.

For example, there are communities for volunteer firefighters, unionized letter carriers, university professors and administrators, and others. Costs are generally lower because they are subsidized by the founding organizations. The best way to find out whether you would fit into one of these communities is to ask the union or professional organization that represents the interests of retired workers to guide you.



TIP

Affinity communities may be based on other shared interests beyond employment, such as travel, sports, or hobbies. Ask yourself: Is this connection really important to me? Do I want to spend most of my time with people who feel the same way I do, or who worked in the same industry? It may be a wonderful match or a little too much of one thing.

Cohousing arrangements

Cohousing is a community-development effort as well as housing arrangement. It may be initiated by a group of neighbors or friends. Some cohousing projects are started by housing developers. Cohousing is different from NORCs. In NORCs, people have aged in place, and service programs can be created around their existing neighborhood. The Village concept is similarly built around existing communities. Cohousing is a designed community.

An idea that started in Denmark, this option involves a group of friends or neighbors who live in separate houses and manage their own finances but work together to design and manage their own community. According to the Cohousing Association of the United States, cohousing has six defining characteristics: participation in the planning process, neighborhood design, common facilities, resident management, nonhierarchical structure and decision making, and no shared community economy (members aren't paid for their contributions to the community). There are entry fees and monthly charges.

The potential benefits include the mutual support that members can provide and the village-like atmosphere that is part of the cohousing philosophy. Opportunities for multigenerational living are also important for some families with grandparents or other older relatives. There are, of course, downsides. Cohousing can be expensive, especially if you don't use all the common services. Privacy is limited, and the community may have more or less stringent rules, especially about selling property.



TIP

The Cohousing Association's website has a directory of communities by state. These sites are concentrated in Western states like California and Washington, but there are some examples throughout the country. And if you are energetic, you can start a cohousing project yourself. To help guide you, check out www.cohousing.org.

House sharing

On a more informal scale, sometimes friends choose to live together and take care of one another as they age. There are even websites for older people looking to share housing. While this idea may be appealing, it takes a good deal of organizational and management skills to make it work. It also depends a lot on each

person being mentally sharp, reasonably healthy, and cooperative in nature. This may be true at the outset, but people and circumstances change. Before entering a house-sharing arrangement, have everyone agree in writing on the basic house rules such as how the common rooms will be used, when and how bills will be paid, and any special considerations such as allergies, pets, and visitors.

So far this idea seems to appeal mostly to women who are single or widowed, although historically men who were separated from their families because of work or illness organized themselves into similar arrangements.

Group homes

Called, variously, residential-care homes, adult family homes, adult foster care, personal-care homes, and board-and-care homes, these are houses in residential neighborhoods that can usually accommodate a small number of people. Typically, the residents have a bedroom but not additional private space. The owners provide meals and some assistance with ADLs (activities of daily living). These homes are much less expensive than assisted living, but they don't provide the same range of services. In some states, Medicaid may pay for a group home for eligible people. If you're considering this option, make sure the home is licensed by the state.



TIP

Investigating this type of housing involves many of the same steps as looking at assisted living or other group settings. However, these are formerly private homes, operated by private individuals, and their reputation, credentials, and training are particularly important. As in assisted living, visits at different times of day are crucial. Some questions you may want to ask are about food preferences and special diets, whether pets are permitted, television and telephone access, and whether and when guests are permitted.

- » Honing your driving skills and adjusting your driving habits
- » Making your car safer
- » Determining when to give up driving
- » Considering other ways to get around

Chapter 6

Getting Around: Transportation Options

We can take for granted the independence, flexibility, and freedom of hopping in our car to get around: to run errands, visit friends, go to a restaurant, get to work. But as we age, our reflexes may not be as quick, our bodies not as flexible, and our vision not as keen, all making driving more challenging. This chapter covers how you can assess your driving habits, or those of your older relative, and how you can introduce the topic of safe driving before it becomes a critical concern.

You also discover ways you may adjust your driving habits and take courses to sharpen your driving skills. With new technology, you may be able to make your car safer or purchase one that incorporates more safety features. And if you limit or stop driving, there are transportation options to get you places: family and friends, public transportation, paratransit, car services, volunteers, and paid drivers. You find out about all that here.

Judging Whether Driving Is Still Safe

Older drivers are, by and large, safe drivers. They are more likely to wear seatbelts than younger drivers, and they are not as prone to speeding, driving under the influence of alcohol or drugs, or risk taking. They are less likely to text or talk on the phone while they drive. Still, when older drivers are involved in accidents, they are more likely than younger drivers to suffer serious trauma and to die.



WARNING

The reality is that aging changes reaction times, vision, and distance perception. In addition, medications may affect driving ability. The label on the pill bottle may warn, “Do not operate heavy machinery while taking this drug,” but some people do not realize a car is considered heavy machinery.

Many older drivers adjust their own driving habits to take account of these changes. They drive less at night, stay closer to home, avoid driving in heavy traffic or bad weather, and drive more slowly. Even with these adjustments, older drivers may be at risk not just from their own driving but also from other drivers who create situations that require quick thinking and rapid responses. Think of how many near misses you have experienced or witnessed as drivers zip through stop signs or make left-hand turns without checking for oncoming traffic. Speedy reactions and your ability to anticipate events may have meant the difference between safety and harm for you or others.

Watching for warning signs of unsafe driving

You should give up driving only if there are real and specific safety concerns. Age alone is not a reason to curtail driving. To find out whether there is a problem, watch for the warning signs in the following list. If you have concerns about an older relative, drive with them and note safety lapses with specific incidents and dates.



TIP

AARP, with the MIT AgeLab and The Hartford Center for Mature Market Excellence, created a checklist of 28 warning signs for older drivers. You can use the items on the checklist to observe an older person’s driving over time and monitor it for a pattern of warning signs and an increase in frequency.

Here are what I consider to be the top warning signs that someone shouldn't be driving anymore, culled from the 28 signs:

- »» Difficulty turning to see when backing up
- »» Riding the brake
- »» Signaling incorrectly
- »» Parking inappropriately
- »» Hitting curbs
- »» Failing to notice traffic signs
- »» Having trouble navigating turns
- »» Moving into the wrong lane
- »» Getting scrapes and dents on cars, garages, and mailboxes
- »» Getting confused at exits
- »» Confusing the gas and brake pedals



REMEMBER

The last item — confusing the gas and brake pedals — is frequently cited as the cause of serious accidents involving older drivers, often resulting in injury to pedestrians and property damage.

If you see any of these signs (or even if you don't so far), thinking about options and, if you have an older relative, starting a conversation about safe driving makes sense. The next section helps you open that touchy subject.



TIP

A driver safety course, such as the AARP Smart Driver course, offered in classrooms and online at www.aarp.org/drive, can help drivers hone their safety skills and be more aware of their limitations and challenges. Taking the course with a friend (or you) may encourage your relative to take it as an educational experience, not as a threat to independence. Many states offer car insurance discounts to motorists who complete the course.

For more advice on how to assess someone's driving, AARP Driver Safety offers a free seminar called "We Need to Talk," developed based on information created jointly by The Hartford and the MIT AgeLab. The seminar is available in both English and Spanish and can be viewed online at www.aarp.org/weneedtotalk.

Starting the conversation

Talking about safe driving to a relative who may have taught you the rules of the road is not easy. Ideally, conversations about safety should start before there is a problem. Introduce the topic gently. This talk is best done in a nonjudgmental and nonthreatening way. A trusted person, whether it's a family member or someone else, can initiate this conversation. A spouse or adult child may be a good choice (or not, depending on the relationship). Older drivers seem to respond best to family or doctors. The strength of the trust between the two people is what counts.

While you want to address the topic before it's emotionally charged, if there is a valid safety concern, that conversation should begin now, and better before an accident than after one. Don't put off the talk simply because you're concerned about hurt feelings.



REMEMBER

This will probably not be just one conversation but a series of talks. The most important part of the conversation will be listening and validating your relative's concerns.

Here are some ways to open the conversation:

"I'm worried about your getting lost."

"With so many bad drivers on the road, I'm concerned about your safety. Can we talk about what you can do to stay safe?"

"I know you are on some new medications. Have you talked to the doctor about whether they affect driving?"

"Do you think you may need new glasses? I noticed that you almost missed the exit sign."

Unless the situation is really an accident waiting to happen, use the opportunity to talk about classes to fine-tune driving skills such as AARP's as well as safe driving habits and ways to adapt the car (see more about these in the next section). Later in this chapter, I come back to the question of what to do when an older person absolutely refuses to make any adjustments.



TIP

If you and your older relative agree that driving doesn't feel as safe as it used to, a good first step can be to set up a driving evaluation. A comprehensive driving evaluation can be arranged through a local occupational therapy driving rehabilitation specialist.

Occupational therapists can identify the physical, visual, and cognitive challenges the individual faces and can recommend ways to limit risks. Visit the American Occupational Therapy Association web page to find a specialist in your area: www.aota.org. A comprehensive driving evaluation can also be arranged through your state's department of motor vehicles. However, many older drivers may be wary of going to the DMV because it has the power to immediately revoke a license.

Making Your Car Fit You

Experts have found that as we age, changes in vision, flexibility, strength, range of motion, and height can make us less comfortable and reduce our control behind the wheel. There are adjustments you may be able to make to your car.

CarFit, an educational program developed by the American Automobile Association, AARP, and the American Occupational Therapy Association, can help educate drivers to become safe and comfortable in their cars. CarFit organizes community events at which technicians and volunteers discuss safe settings to make the car fit the driver. The service takes approximately 20 minutes. Go to car-fit.org/carfit/RegisterCarFit for information about events around the country.

The most common adjustments are to mirrors, steering wheels, and seats. Some adjustments can be done easily, such as these:

- » Your line of sight should be at least 3 inches above the top of the steering wheel.
- » There should be 10 inches between your breastbone and the air bag in the steering wheel.
- » The center of the head restraints should be about 3 inches or less from the center of the back of your head.

Systems for emergencies, such as OnStar in General Motors vehicles, are also easy to obtain. They call for help, giving your location. Other systems are available for different manufacturers. They are paid for on a subscription basis.



Performing regular maintenance on the car is critical. Set up, or have your older relative set up, a schedule with a trusted mechanic to go over the car at regular intervals, even if it's not being driven a lot.

Increasing safety with new technology

In addition to adjustments to make your car fit you, today's technology can help make a car (and its driver and occupants) safer. Your old car probably already has air bags and anti-lock brakes, and perhaps a GPS system that gives directions and alerts about approaching exits and turns. But there's more.

The Hartford and the MIT AgeLab, which has been a leader in driver safety for older people, convened a group of experts to review the past decade of research and innovations in driver safety. Following are the technologies they recommend:

- » **Smart headlights:** Adjust the range and intensity of light based on how far away the traffic is and reduce glare
- » **Emergency-response system:** Offers quick assistance in case of a medical emergency or collision
- » **Reverse backup camera and monitoring system:** Warns drivers of objects to the rear of the vehicle to help drivers judge distances and back up safely
- » **Blind-spot warning system:** Alerts you to oncoming traffic by a flashing light in your side-view mirror and a beep or steering wheel vibration
- » **Lane-departure warning:** Helps drivers avoid wandering into another lane
- » **Vehicle-stability control system:** Helps keep the car in the intended line of travel, especially when the driver underestimates the angle of a curve or encounters severe weather
- » **Assistive parking system:** Enables vehicles to park on their own or indicates distances to objects, making parking easier and reducing stress
- » **Voice-activated system:** Allows drivers to access features by voice command so they can keep their eyes focused on the road

- » **Crash-mitigation system:** Detects when the car may be in danger of a collision
- » **Drowsy driver alerts:** Monitor the degree to which a driver may be inattentive and alert them to pay attention

Some of these devices may be standard in a new (probably more expensive model) car or can be installed by a car dealer. Generally, each manufacturer prices these technologies as part of an equipment package. For example, smart headlights may be part of an “all-weather” package because of their capacity to compensate for poor weather conditions as well as bends in the road.

Choosing a new vehicle

In addition to the new technology in the preceding section, when someone buys a new vehicle, the National Highway Traffic Safety Administration (NHTSA) recommends looking for features that consider the physical and visual challenge of aging:

- » High or extra-wide doors
- » Adjustable foot pedals
- » Large interior door handles
- » Oversized knobs with clearly visible labels
- » Support handles to assist with entry and exit
- » Large or adjustable-size print for dashboard gauges
- » Seat adjusters that can move the seat in all directions; the driver’s line of sight should be 3 inches above the adjusted steering wheel
- » Dashboard-mounted ignition rather than steering column-mounted ignition

Modifying vehicles

Adjustments such as pedal extensions or other adaptive equipment may require technical assistance. The American Occupational Therapy Association has a directory of driving-rehabilitation specialists at myaota.aota.org/driver_search. Also see the website of the Association for Driver Rehabilitation Specialists, www.aded.net, for professionals in your area who can diagnose driving problems and help drivers learn safer practices.

Having a disability can make driving an ordinary car difficult or impossible, so you may need a specially adapted vehicle. It may be a sedan or minivan with a wheelchair lift, a car with special steering or braking equipment, or any number of other adaptations. The NHTSA has guidelines on adapting motor vehicles for older adults and alternative guidelines for people with disabilities, which you can find at www.nhtsa.gov/sites/nhtsa.dot.gov/files/documents/adapting_motor_vehicles_brochure_810733.pdf.

In considering a new vehicle or adaptations, the NHTSA suggests that you consider the following issues:

- » Does the vehicle have the cargo capacity (in pounds) to accommodate the equipment you require?
- » Is there adequate parking space at home for loading and unloading the vehicle?
- » What additional options would be necessary to operate the vehicle safely?



TIP

If a third party — an insurance company, a state agency, a non-profit organization, or the VA — is paying for a new vehicle, adaptive devices, or other modifications, find out whether there are any limitations on what may be covered. Get a written statement on what a funding agency will pay before you or your relative agree to buy or make the changes.



REMEMBER

A driver's license may need to be modified to note any restrictions. And the insurance company should be notified of the adjustments.

Knowing When It's Time to Give Up the Keys

When all the safe driving courses, gentle conversations, and vehicle adaptations have failed to make you or your older relative a safe driver, then you need to act. It's not easy to give up the keys, but there are ways to make it work.

If it's for your older relative, AARP's "We Need to Talk" brochure indicates that car accidents, near misses, self-regulation of driving, and health changes provide opportunities for talking about driving. That brochure can help you with these conversations.

Make sure to identify and practice alternative transportation (see the next section). And take special care to listen to the person's feelings about missing the freedom and independence when losing the ability to drive.

Note safety lapses you observed when driving together, indicating specifics incidents and dates. Keep the emphasis on safety and health. Say things like "I know you would feel terrible if someone was hurt when you were driving" or "Even if you were not at fault in a collision, you can be seriously injured or die." Concern for others may be a stronger motivation than concern for oneself. Tactfully mention, without dramatizing the point, that an accident would create a major financial and possibly legal burden. Acknowledge how difficult this transition is. With gentleness and concern, a decades-old driver can become a more or less willing passenger.



TIP

You may be able to enlist the support of a doctor to limit or forgo driving altogether, particularly if your relative has some medical or cognitive condition, such as Parkinson's or Alzheimer's disease, that affects driving. Your relative may be more willing to accept intervention if you identify the disease as the problem rather than the driver's skill. A person with dementia may get lost even in familiar places, in addition to the lapses in judgment that are often symptoms of this condition. The driving evaluations mentioned earlier in this chapter may provide a factual basis for the recommendation from a third party that it is time to give up the keys.

If all else fails, you may have to consider disabling the car, failing to renew the driver's license or having it revoked, canceling the insurance, or taking away the keys. Even these measures may not be enough, as some very determined older people will find ways around them, such as calling a mechanic to fix the car or driving without a license or insurance. Taking the car away is a final step.

Finding Alternatives to Driving

Housing and transportation are two basic needs, and they are often connected. People often live in neighborhoods that aren't walkable, bikeable, or near public transportation. Housing in areas close to public transportation may be unaffordable for older

people on fixed incomes. It's not surprising that so many older people don't want to give up their driving, which often results in feeling a lack of freedom and independence. Depending on where you or your older relative lives, there may be a few or many alternatives for getting around.

There are numerous options in addition to bicycles and walking:

- » Public transit (buses, light rail transit, trains/subways)
- » Paratransit (reservations-required vans or cars for people who cannot drive or who have disabilities)
- » Private transit (taxis, car services)
- » Specialized transit (programs organized by hospitals, senior centers, and religious or volunteer organizations to serve particular populations)

I discuss all these options in the following sections.

Public transportation and paratransit options

Easterseals, a nonprofit organizations, has a guide for caregivers on mobility and safety for people with disabilities at www.easterseals.com/explore-resources/for-caregivers/. Older adults with limited mobility will find this guide useful.

The TREDs (Training, Research and Education for Driver Safety) program at the University of California–San Diego also has several brochures about this subject. You can find it at <http://treds.ucsd.edu/wp-content/uploads/2019/01/Resources-for-Safe-Driving-DEC-18.pdf>.

Look into the public transportation options in your community, including buses, subways, and rail options. Check to see whether the public transportation in your community is set up for people with limited mobility. For some of the oldest transit systems in the United States (like in New York City), constructed before the Americans with Disabilities Act (ADA), access for people with disabilities can present a challenge. In its extensive subway system, not all stations are equipped with elevators, so a person who has difficulty with stairs may be able to get down to the tracks to get on a subway train but find that there is no elevator service at the destination station. Buses are now more likely to have

lifts or ramps for wheelchairs or walkers and specially designated seats for passengers who are older or have a disability. Still, this adaptation isn't universal. And buses have designated routes and stops, which may or may not be convenient.

Get used to using public transportation before you need it. You can get a group of people together, or ask for volunteer help from students or family members or a nonprofit, to take a day tour of public transit to find out how to get around, pay the fare, signal for stops, and disembark.

Paratransit is another option. The ADA requires transportation agencies that provide fixed-route services (bus or train) to also provide paratransit services to people with disabilities who live within three-quarters of a mile from the fixed routes. These restrictions mean that not all older people will qualify for public paratransit services. Look for these standards:

- » **Availability:** Check the hours, such as during days, evenings, and weekends.
- » **Accessibility:** The transit comes to the door, or the bus stop is close by, and the vehicle is easy to enter.
- » **Affordability:** Fees are low enough for people on restricted budgets, with options for discounts.
- » **Destination:** Some services link only to specific places, such as going to the doctor or shopping; others are more flexible and go where the passenger wants to go within the service range.
- » **Assistance:** Check the types of assistance offered. Some services provide mechanical assistance (buses that have wheelchair lifts or ramps and special seating; paratransit drivers who assist passengers getting on and off).
- » **Information:** Find out about the routes and how to make arrangements to use it.
- » **Socialization:** While bus and van drivers should focus on the road, the way they greet passengers and help them on and off makes a difference. On a familiar route, passengers should feel free to chat, share their experiences, comment on the journey, and generally make the trip enjoyable. Some may prefer not to join in, and that should be respected as well.

You can use these standards to evaluate the options available in your area. Check online or by phone with the local government office that runs the public transportation system to obtain a map of the system, which may or may not have up-to-date information on accessibility features.



TIP

Area Agencies on Aging and Aging and Disability Resource Centers may offer fare assistance programs for eligible riders who can purchase vouchers at a discounted rate. The vouchers can be used to pay for services from participating transportation providers, including public transportation, taxi companies, or others.

Private options

Where public transportation isn't available or appropriate, some private services can fill the gap. Older people may balk at the expense of paid transportation, but maintaining a car and paying for gas and insurance is much more expensive than an occasional ride. Following are some of the more popular options:

- » **Family and friends:** Probably most older people get rides from family, friends, and neighbors from time to time. One person may offer to take you shopping or to religious services. Another may volunteer to go to the doctor and wait until the visit is finished. These are the traditional ways people who don't drive have been helped over the years, and they still work. Be aware of whether these volunteer drivers are themselves of an age or condition in which their driving capacity may be at risk.
- » **Taxis:** Taxicabs offer a common alternative to driving. Some cities restrict licensed cabs to picking up passengers on the street; others have some way to call from wherever you are. Some taxi companies have wheelchair-accessible vehicles.
- » **Smartphone app car services:** The newest variety of car service, available in most cities, uses a smartphone app. Uber and Lyft are the most well-known. The app identifies your location and sends the nearest driver to pick you up. Fees are set in advance and paid for by a credit card on file. Tipping is optional. Uber has introduced Uber Health, a service available through some healthcare organizations, that arranges rides for doctor appointments. See www.uberhealth.com/ for more information.

GoGoGrandparent is a company that, for a fee, lets you order a smartphone app car service without the smartphone app. The rider calls a number, 855-464-6872, which relays the request to a dispatcher from a service such as Uber or Lyft: gogograndparent.com.

- » **Car services:** This option is like a more upscale taxi. The cars are generally more comfortable, although more expensive than taxis. Some are wheelchair-accessible. If you set up an account with a credit card, you can be billed at the end of the month, which gives you a record of expenses.
- » **Supplemental transportation programs (STPs):** STPs are nontraditional transportation services for older adults who don't drive and others who need assistance. Most STPs provide door-to-door rides, and some arrange for a driver to stay with passengers until they are ready to go home. Some STPs are organized by religious institutions or other community groups.
- » **Volunteer programs:** Programs organized by faith-based organizations or private agencies often have a network of volunteers who provide transportation for shopping, doctor's appointments, and recreation. They may offer one-way, round-trip, or multistop rides, usually at no cost or on a donation basis.
- » **Hiring a driver:** Some people may have the option of hiring their own driver when needed (as in the movie *Driving Miss Daisy*). It need not be a full-time position. If you hire a driver, make sure the person's driver's license and insurance are valid and up-to-date.
- » **Transportation provided by independent or assisted-living facilities, Villages, or other residence- or community-based organizations:** These options have become increasingly important and desirable for older individuals and are often used to get to and from doctors' offices, entertainment sites such as movie theaters, and so on.



TIP

When thinking about asking family or friends to help you get from Point A to Point B, ask these questions:

- » Are people available to provide rides at the times required?
- » To what extent are family or friends able or willing to provide rides?

- » Do people provide the rides willingly, or do they resent having to adjust their schedule?
- » Can the older person trade something for a ride (making dinner, taking the driver to lunch, paying for gas)?

You and your older relative can answer these questions yourselves. But to get the information for the public or other private options, you should do some research. To find out what is available in your community, check with the local Area Agency on Aging, the state Aging and Disability Resource Center, senior centers, healthcare providers, and others who may know about options. Giving up the keys should lead to new ways of getting around, not the end of living fully in the community.

- » Distinguishing Medicare and Medicaid
- » Seeing what Medicare benefits contribute to a future care plan
- » Understanding Medicaid eligibility and community services and supports

Chapter 7

Unraveling the Rules of Medicare and Medicaid

You may be thinking about how Medicare and Medicaid will help pay for your long-term needs as you age.

Perhaps you've heard that Medicare doesn't cover long-term care. What most people mean by this declaration is that the federal Medicare program doesn't cover a long stay in a nursing home or 24-hour personal care at home or in an assisted-living facility. Medicare does, however, cover a short stay for rehabilitation therapy as well as many of the healthcare services you need to live safely at home and in the community.

Medicaid, a federal-state program for low-income individuals, does cover long-term care in nursing homes and many home- and community-based services, but its eligibility and other rules vary by state and set stringent limits on income and assets. Policymakers call people who are eligible for both Medicare and Medicaid by the awkward term *duals*. That means if you're eligible for Medicare and Medicaid, you can coordinate benefits from both programs.

Understanding the framework of these public programs is the first step in figuring out how they may or may not apply to you and how they may relate to other kinds of healthcare or long-term care insurance. Dive into this chapter to discover how these programs work.



REMEMBER

Medicare and Medicaid rules are subject to change. You can check www.medicare.gov, www.medicaid.gov, and your state Medicaid agency for information. Other sources of information are the Medicare Rights Center (www.medicarerights.org/), which has a help line for questions, and the Center for Medicare Advocacy (www.medicareadvocacy.org/), which has useful publications and updates on court cases.



TIP

As you start to navigate public healthcare programs, keep in mind that your State Health Insurance Assistance Program (SHIP) is a valuable resource. The SHIP advisers can guide you through the maze of Medicare, Medicaid, and other insurance plans. You may find that you're eligible for more than you realized. Find your state SHIP at www.shiptacenter.org/.

The Distinction between Medicare and Medicaid

Medicare pays for the medical care needed by someone who has a chronic condition or a disability but does not pay for the nonmedical services that person needs. (An exception is a recent change to Medicare Advantage plans, described later in this chapter.) Medicaid, however, pays for both for eligible low-income people.



REMEMBER

Here is an essential but still often misunderstood distinction between Medicare and Medicaid:

- » **Medicare:** A federal health insurance program for people age 65 and older and for younger people with certain conditions and disabilities. More than 61 million Americans are enrolled in Medicare.
- » **Medicaid:** A federal-state program that pays for healthcare and long-term care for low-income people who meet a certain threshold. Over 79 million Americans, including 8.9 million children, receive healthcare through Medicaid over the course of a year.

For more comprehensive information on Medicare, see AARP's *Medicare For Dummies* by Patricia Barry (published by Wiley).

Looking at Medicare Basics

Medicare is the main source of payment for medical care for adults 65 and older. If you live in your own home, assisted living, a multigenerational home, or some other non-nursing-home setting, you need access to medical service providers for primary care, preventive care, and management of chronic conditions; hospital care; post-hospital rehabilitation services and home healthcare; and emergencies, as well as prescription drugs and, for some conditions, durable medical equipment. Medicare generally pays for this necessary medical care.

In addition to Medicare eligibility parameters, the following sections also cover Medicare's two options: Original Medicare and Medicare Advantage plans. I also discuss Medicare's role in providing necessary medical care services.



WARNING

Beginning in April 2018, Medicare started issuing new identification cards to all eligible beneficiaries. The main difference is that your Social Security number (SSN) is no longer your ID number. This change is intended to prevent misuse of your personal information. But it has also given rise to new scams, mostly involving attempts to get you to pay for your Medicare card (it's free) and to get access to your personal information. Ignore any callers who claim to be from Medicare. Another change is that gender is no longer listed on the card. If you already have a Medicare Advantage, Medigap, or prescription drug plan ID card, those IDs are different from the SSN.

Are you eligible for Medicare?

If you are 65 or older, you're probably already enrolled in Medicare. Enrollment is automatic when you start collecting some form of Social Security benefits. If you are 65 or older and not yet collecting Social Security benefits, you can enroll in Medicare online, over the phone, or in person through the Social Security Administration.

Not everyone over 65 is automatically eligible for Medicare. You must be a U.S. citizen or a legal resident of the United States for more than five years. Residents of Puerto Rico are eligible. If you (or a spouse) have worked at least a total of ten years (40 credits) and contributed to Social Security under the Federal Insurance Contributions Act (FICA) through your employers, you are eligible.



TIP

Earning 40 work credits means only that you don't have to pay monthly premiums for Part A services. Anybody who is a citizen or legal resident for at least five years can get Part B and Part D services by paying premiums for them like everybody else.



REMEMBER

The Affordable Care Act (ACA, also commonly called Obamacare) doesn't affect Medicare eligibility. If you are enrolled in Medicare, you don't have to do anything. The ACA did make some changes to Medicare: Some preventive measures such as mammograms and colonoscopies are now free, and a timetable has been set for closing the so-called doughnut hole in Part D for prescription drugs (discussed in the later section "Prescription drug coverage").

The U.S. Supreme Court ruling in June 2013 that struck down Section 3 of the Defense of Marriage Act has implications for Medicare eligibility. The Act had defined a *spouse* as a "person of the opposite sex," so the court's decision opens Medicare eligibility and benefits to same-sex couples. The Department of Health and Human Services has begun to issue specific policy changes, including same-sex married couples' rights under Medicare Advantage plans to reside in the same nursing home.

If you are uncertain whether you or your relative qualifies for Medicare, contact Social Security at 800-772-1213 or go to www.medicare.gov/eligibilitypremiumcalc/. This website also helps you calculate your premium. The Medicare Rights Center has a useful fact sheet titled "Medicare Q and A" on eligibility and the timing of enrollment at www.medicarerights.org/PartB-Enrollment-Toolkit/Part-1-QA-General.pdf.

What's included in Original Medicare

Original Medicare includes Parts A, B, and D benefits. (Part C applies only to Medicare Advantage and is just another way of packaging Parts A, B, and D benefits. See the next section for details on Medicare Advantage plans.)

Parts A, B, and D

Here is a breakdown of Parts A, B, and D:

» **Part A:** Medicare Part A covers inpatient care in a hospital, rehabilitation services in a skilled nursing facility or rehabilitation hospital, hospice care, home healthcare (under certain conditions), and inpatient care in a religious nonmedical healthcare institution (a place for Christian Scientists who need assistance but have religious objections to conventional medicine). Medicare Part A does not require additional premiums for eligible beneficiaries; if you do not have enough working quarters to qualify, you can enroll and pay a monthly premium. There is a *deductible* (amount you pay before Medicare starts paying) if you are hospitalized; in 2021 this is \$279 or \$471 a month depending on how long you or your spouse worked and paid Medicare taxes. This website — www.medicare.gov/your-medicare-costs/medicare-costs-at-a-glance — gives costs for all Medicare-covered services. Be sure to check with your provider to verify the costs of any service.

Medicare imposes a “lifetime reserve”; when you reach that amount, you pay all costs. However, reaching the lifetime reserve is unlikely to occur because hospital stays these days are generally very short, and patients who require further care are frequently transferred to a rehabilitation program in a skilled nursing facility (SNF). If this happens, it doesn't mean you have been placed permanently in a nursing home. Although the Medicare benefit period in a rehab setting ends at 100 days, you may be discharged much earlier, perhaps within two to three weeks. You don't have to pay any fees for the first 20 days of each benefit period. In 2021, for days 21 through 100, you pay a coinsurance amount per day of \$185.50, and if you stay past day 100, you pay all costs for each day, unless you have additional insurance that covers these costs.

To be eligible for Medicare coverage of a rehabilitation program in a skilled nursing facility, you must have been hospitalized as an inpatient for three days before the transfer. Some hospitals have been classifying patients as being in *observation status* — that is, not formally admitted to the hospital, even though they may be in a bed on a hospital unit getting the same treatment as an officially admitted patient.



WARNING

You should receive a notice that you are in observation status called a MOON (Medicare Outpatient Observation Notice). This has financial implications; their stay is not covered under Medicare Part A, which has a one-time deductible for the stay, but under Part B, which bills for every service separately as if the hospital were an outpatient setting. Moreover, days spent in observation do not count as inpatient days toward the three-day nursing facility requirement, so the patient is responsible for the entire cost of the rehab stay. This policy is being contested and may change, but for now it is worth asking at every hospital stay whether the patient is admitted or under observation.

- » **Part B:** Medicare Part B is an optional component that helps cover medically necessary services like doctor's visits, outpatient care, durable medical equipment, and many preventive services like flu shots. You pay a monthly premium to be enrolled to obtain coverage for these Medicare services. But Part B is heavily subsidized, so unless you have very good private insurance, it almost always makes sense to choose this option.

Original Medicare Part B does not cover routine vision or dental visits or products like hearing aids.

- » **Part D:** Medicare Part D, which covers prescription drugs, is also optional but strongly advised. You pay a monthly premium, which changes every year. If you receive Social Security benefits, your Medicare premium for both Parts B and D are deducted from the check.



REMEMBER



TIP

Unlike Part A, premiums for Parts B and D are set at a higher level for people with higher incomes. The higher premiums in 2021 start at \$88,000 per year for an individual and \$176,000 for a couple. For more information, see www.medicare.gov/your-medicare-costs/part-b-costs.

What Medicare doesn't pay for

Medicare doesn't pay for everything. Even if it does cover a service, you generally pay the following fees:



REMEMBER

- » A deductible (a certain amount of actual medical costs you incur before insurance starts to pay)

- » Coinsurance (your share of these costs after the deductible has been reached, typically 20 percent)
- » Copayments (the fixed amount you pay, for example, at a doctor visit)

Many people purchase Medicare Supplemental Insurance (Medigap) to help pay for these additional expenses. These policies are offered by private insurance companies and must meet federal and state requirements. Medicare has information on how to find Medigap policies in your state at www.medicare.gov/supplement-other-insurance/medigap/whats-medigap.html.

What you get with Medicare Advantage plans

Medicare Part C offers an alternative to Original Medicare called the *Medicare Advantage program*, a collection of health plans (such as Health Maintenance Organizations and Preferred Provider Organizations) that combine Parts A and B services (usually with Part D prescription drug coverage) in their benefit packages. The plans are offered by private companies with Medicare approval. They must cover all the services in Original Medicare but may also offer extra coverage, such as vision, dental, hearing, and health and wellness programs. Medicare Advantage plans set their own fee schedules and choose their own network of providers and facilities; this is important information to consider when you're choosing a plan.



TIP

The 2018 Chronic Care Act passed by Congress as part of the Bipartisan Budget Act of 2018 includes a provision that gives Medicare Advantage plans more flexibility in covering nonmedical products and services, such as bathroom grab bars and wheelchair ramps. It also expands telehealth services so people who are unable to get to a doctor's office can communicate by web-based services. There is no requirement that Medicare Advantage plans offer these add-ons and no special funding for them, so each plan will make its own choices.



REMEMBER

In Original Medicare — a fee-for-service arrangement — you go to a doctor who participates in the program and pay a copay, and the doctor bills Medicare for the visit and any tests or procedures that were performed. Medicare Advantage plans receive a set amount every month for each person enrolled in the plan,

whether they use many services or just a few. The plan can charge different copays and have different rules about whether you need a referral to see a specialist, for example, or whether you can go only to doctors or hospitals that belong to the plan. There are several different kinds of Medicare Advantage plans, and their rules, costs, and benefits differ and can change each year. You can change plans once every year and at other times in certain circumstances.



WARNING

If you enroll in a Medicare Advantage plan, you can't buy a Medigap policy. This kind of insurance can be used only with Original Medicare and can't be used for any expenses under a Medicare Advantage plan. However, if you drop your Medigap policy to join a Medicare Advantage plan and then decide to go back to Original Medicare, you may not be able to get the Medigap policy reinstated.

For more information about Medicare Advantage plans, go to the Medicare Plan Finder at www.medicare.gov/find-a-plan.

Prescription drug coverage

Medicare Part D covers prescription drugs, which is often an expensive part of medical care. Following are the two main ways to get prescription drug coverage:

- » Part D plans, which add drug coverage to Original Medicare
- » Medicare Advantage plans, which include Part D prescription drug coverage (MA-PDs)

If you're choosing among Part D plans, you need to consider a few variables:

- » Are the drugs you take on the plan's formulary (list of drugs)?
- » Is the pharmacy you generally use in the plan's network?
- » Does the plan require you to use generic rather than brand-name drugs, or to give certain drugs a trial before it will approve more expensive ones?
- » Do you have to pay a deductible or copayment for drugs?
- » Are financial-assistance plans available?



Most Medicare Part D plans have a so-called doughnut hole, now called the *coverage gap*, that begins after you and your drug plan have spent a certain amount for covered drugs. In 2021 that amount is \$4,130. After you're in the doughnut hole, in 2021 you pay 25 percent of the plan's costs for covered brand-name drugs. You also pay 25 percent for generic drugs, but only the amount you pay counts toward the coverage gap. What you've paid from the beginning of the year — deductibles, coinsurance, and copays (but not the drug plan premiums) — counts toward getting out of the coverage gap, as do any discounts for brand-name drugs that you get in the gap. After you reach \$4,500, catastrophic coverage takes over and pays 95 percent of Part D drug costs. Under the Affordable Care Act, the doughnut hole was supposed to shrink every year until it disappeared in 2020, but it has continued into 2021.

After you've spent \$6,550 out-of-pocket in 2021, you're out of the coverage gap. Then you automatically get catastrophic coverage. It assures you only pay a small coinsurance amount or copayment for covered drugs for the rest of the year.

Even with Medicare Part D, prescription drugs can be very expensive. Financial assistance may be available from Medicare, your state, pharmaceutical companies, or charities. Here are some resources for financial assistance:

- » **Extra Help:** Medicare's Extra Help program provides low-cost Part D coverage for people with incomes and assets under a certain level. Income limits are higher if you have dependents living with you or if you live in Alaska or Hawaii. Assets include money in savings or checking accounts, stocks, bonds, and other investments, but not your home, car, or household items. If you qualify and join a Medicare drug plan, you get help paying for your monthly premium, yearly deductible, coinsurance, and copayments. If you have Medicaid and live in a nursing home, this drug coverage is free. To apply for Extra Help, go to www.socialsecurity.gov/i1020 or call 800-772-1213.
- » **State Pharmacy Assistance Programs:** Many states have State Pharmacy Assistance Programs (SPAPs) that help some people pay for prescription drugs based on financial need, age, or medical conditions. To find out what is available in your state, contact your State Health Insurance Assistance Program (SHIP). Find your state SHIP at www.medicare.gov/contacts/organization-search-criteria.aspx.

- » **Pharmaceutical assistance programs:** Many major pharmaceutical companies help people who are taking their drugs but can't pay the full price. There is a list of drugs and potential pharmaceutical or patient assistance programs at www.medicare.gov/pharmaceutical-assistance-program/. Even if the drug is not on the list, try calling the company to see what help you can get. The formal request must be made by a doctor.
- » **Charity programs:** Charity programs include organizations that help people with low incomes pay for prescription drugs. These organizations often serve people with a particular disease, such as cancer or neurological conditions. The Medicare Rights Center lists some of these charities at www.medicarerights.org/pdf/copay_charities.pdf.

Private insurance (such as retiree benefits) in addition to Medicare may help with prescription drug coverage. Check with your plan to see how it coordinates benefits. Medigap supplemental insurance, however, doesn't cover drug expenses.



TIP

The Medicare Rights Center has a comprehensive guide to financial assistance for prescription drugs with information by state. You can access the guide at www.medicareinteractive.org/pdf/SPAP-Chart.pdf.

Durable medical equipment coverage

Medicare Part B covers durable medical equipment (DME), which includes devices like canes (except white canes for blind people), walkers, wheelchairs, hospital beds, commodes, and other aids that a person with a disability or a chronically ill person needs at home. A walker, for example, that you need only to take a walk down the street would not be covered.

DME can be used over and over, distinguishing these items from disposable supplies like adult diapers, bandages, and sterile gloves that can be used only once. Disposable items like these are not covered by Medicare. However, non-reusable diabetic supplies like test strips and lancets are covered, as are oxygen supplies.



WARNING

Phone or mail offers to supply DME at extremely low costs are likely to be scams. Make sure you're alert to these phony offers and buy only from suppliers that Medicare has approved.



REMEMBER

DME is one of the most confusing parts of Medicare, and the rules keep changing. However, here are some points to remember:

- » Medicare covers DME only when ordered by a physician.
- » The equipment must be ordered from companies that have an agreement with Original Medicare or with a Medicare Advantage plan.
- » Some areas of the country are included in Medicare's Competitive Bidding Program, which is designed to prevent overcharging to Medicare. It applies only to Original Medicare and may mean you have to change suppliers for certain items.
- » If you are in Original Medicare, you are responsible for a 20 percent coinsurance payment of the Medicare-approved amount (which may not be the full price).
- » Some items can be rented rather than purchased. There are special rules for renting oxygen equipment.
- » Medicare pays only for the basic model. If you need a customized wheelchair or a special bed, you must pay the extra charge.
- » Medicare covers repairs and maintenance to keep equipment in good working order, but the rules are different depending on whether you own or rent the equipment. Delays in getting DME repaired are unfortunately common.
- » If your claim for DME that a doctor has ordered is denied by Medicare's contractor in your region (a private insurance company that reviews Medicare claims), you have the right to appeal that decision.

Home healthcare services

Help at home is probably the most-often-needed service for an older adult, and it's the area where Medicare coverage is weakest and private costs are highest. Medicare does pay for some home healthcare services, however, under these conditions:

- » A doctor confirms in writing that he has examined the person within 30 days and that the patient needs skilled nursing care, such as care provided by a registered nurse or physical therapist. Without this signed paper, the home healthcare

agency cannot “open the case” (begin treating the person). The doctor can be a hospitalist or an emergency department doctor (employed by the hospital) or a community-based doctor. The visit must be face-to-face, not a phone conversation or a report from a nurse.

- » If there is a documented need for skilled care, the person may also receive some home care aide services, although usually for a few hours a day or a few days a week.
- » The person is homebound (meaning that leaving the house is hard).
- » The person needs only short-term or part-time skilled services.
- » The services are provided by a Medicare-approved home health agency (HHA). The HHA may have its own home health aides or contract with licensed agencies to provide these workers, but Medicare will not pay for services provided only by licensed agencies or companion agencies.



TIP

The so-called “improvement standard” (denial of physical or occupational therapy because the Medicare beneficiary is no longer making improvements) no longer exists (it was never a regulation even though it was commonly used). As a result of a lawsuit (*Jimmo v. Sebelius*) filed by the Medicare Advocacy Center, CMS has officially ended this practice. The cap on reimbursement for these services has also been lifted, although providers are subject to a review of their fees if they reach a threshold of \$3,000. For more information on this case, go to www.medicareadvocacy.org/medicare-info/improvement-standard/.

Medicaid Ground Rules

Medicaid, a publicly funded healthcare program for low-income families and individuals, is a shared responsibility of the federal and state governments. While eligibility for Medicare is generally based on the applicant’s age, eligibility for Medicaid is generally based on the applicant’s income and assets. Medicaid pays for more than 60 percent of people living in nursing homes. Nearly a quarter of people enrolled in Medicaid are older adults or people with disabilities, but they account for more than 60 percent of all Medicaid spending because they need more and often more expensive healthcare.

The federal government sets basic rules about what benefits must be included in state Medicaid plans and shares the costs. The federal government matches state Medicaid funding on at least a 50 percent basis, but the match may be higher in states with low per-capita income. States set their own eligibility requirements and have considerable flexibility in designing their benefit packages.



TIP

States call their Medicaid programs by different names: Medi-Cal in California, TennCare in Tennessee, and MassHealth in Massachusetts, for example. Some states seem to go out of their way to avoid using Medicaid in their program name. For the name and program offices in your state, go to www.medicaid.gov/medicaid/by-state/by-state.html and follow the link to your state's website.

Are you eligible for Medicaid?

To receive federal funding, state Medicaid programs are required to cover certain populations, such as children in low-income families and pregnant women. Older adults with low incomes and people with disabilities who receive cash assistance through the Supplemental Security Income program (SSI) are eligible in the states that use SSI criteria. (Nine states continue to use more restrictive 1972 welfare eligibility standards.) Eligibility requirements differ considerably from state to state. This website gives you some basic information on eligibility requirements in your state: www.healthcare.gov/do-i-qualify-for-medicaid.

In the past several years, Medicaid programs have been under pressure to control costs, and one way they have done this is to tighten the eligibility requirements. In some places the entry process is very time-consuming and difficult. On the other hand, some states are streamlining the process by making it easier to enroll online or without a face-to-face interview.



REMEMBER

Unlike Medicare, where there are clear federal eligibility standards, Medicaid varies by state. However, there are certain basic approaches:

- » According to federal rules, Medicaid must cover certain populations (such as children in low-income families, pregnant women, and people with disabilities receiving SSI).

- » States set their own, typically stringent, levels for income, often some percentage of the federal poverty level.
- » For adults over age 65 and people with disabilities, all states (except Arizona) limit the amount of assets a person can retain to be eligible for Medicaid; this is usually a small amount, although eligibility may be delayed for individuals transferring larger assets within a “look-back” period prior to applying. (Under the ACA, nondisabled children and nondisabled adults under age 65 are no longer subject to asset limits.)

Medicaid is intended as a safety net, and states take that goal seriously.

Medically needy programs

In addition to income and asset limits, 33 state Medicaid programs have *medically needy* programs that assist people who have high medical expenses but whose income exceeds the maximum threshold for Medicaid eligibility. Older people living in nursing homes and children and adults with disabilities comprise a significant fraction of the 3.2 million people enrolled in these programs.

Eligible participants can subtract their healthcare expenses from their income. States vary in their rules for eligibility and the way they determine the number of months a person must pay these expenses privately before Medicaid kicks in. Some of these people may become eligible for Medicaid directly through the ACA. See the report from the Kaiser Commission on Medicaid and the Uninsured for state-by-state information at www.kff.org/other/state-indicator/medicaid-eligibility-through-the-medically-needy-pathway/.

Exchanges

Starting in October 2013, all states were required to have a new Health Insurance Marketplace or exchange. These are websites where various health plans can offer their policies to prospective consumers. The Marketplace offers information about a range of selected private health plans as well as Medicaid. People with certain income levels can receive subsidies, and the goal is to benefit everyone because of the large risk pool. For more information about your state, go to www.healthcare.gov or see the state profiles at the Kaiser Family Foundation website, www.kff.org/state-health-exchange-profiles.

You may want to ask a family member or friend to help you access the information you need. The ACA also offers funding to local nonprofit organizations, or “navigators,” that may assist individuals with enrollment in the exchange. To find navigators in your area, go to localhelp.healthcare.gov.

Estate recovery



WARNING

Becoming eligible for Medicaid is one challenge; what happens after death can be another. The 1993 federal estate recovery rules require state Medicaid programs to recover from the estate of an individual over the age of 55 certain benefits paid on behalf of a Medicaid enrollee. They may be payments to a nursing home, home- and community-based services, or hospital and prescription drug services. There are limits, however. States cannot recover money from the estate of a Medicaid enrollee who is survived by a spouse, a child under the age of 21, or a disabled child of any age. States vary in how aggressively they pursue estate recovery. It is important to understand the provisions of your state's estate-recovery program. Although the amount recovered for the state is usually very small, it can present hardships for the surviving family members. However, states are required to establish procedures for waiving estate recovery if heirs would experience undue hardship. For more information, see AARP's report on varying estate recovery practices at assets.aarp.org/rgcenter/il/inb137_medicaid.pdf.

What services Medicaid offers

Federal rules require states to provide a basic set of services to Medicaid recipients, including hospital stays, doctor visits, preventive care, laboratory and X-ray services, transportation to medical care, home health services, and nursing-facility care. States have the option of adding, among other things, physical and other kinds of therapy, personal care, hospice, and case management. Prescription drug coverage is optional, as are dental and vision services. Many Medicaid services are designed for children and pregnant women.

Unlike Medicare, Medicaid covers long-term care in nursing homes and in the community through home- and community-based waivers (permission from the federal government to spend money that would have gone to nursing homes or community-based services instead) and other approaches.

States can determine the criteria for nursing home care and home- and community-based services, so a person eligible in one state may not be eligible in a neighboring state. Usually some level of functional limitations is required, like being unable to take care of personal basic needs like bathing, dressing, or going to the toilet. Many nursing-home residents have cognitive problems like dementia, which limits their ability to function independently.

How Medicaid works with home- and community-based programs

Because nursing-home care is so expensive, states have moved toward caring for these individuals in the community. Someone with functional limitations can receive care at home that may include personal care, homemaking services, case management, transportation, and other long-term services and supports. Even with these services, which may be limited by funding or work-force shortages, family members often provide some or most of the care.

Most states have a variety of Medicaid services that operate under different waiver programs from the federal government (for example, programs that include a package of services targeted for people with specific disabilities, such as traumatic brain injury or HIV/AIDS). A waiver means the federal government allows a state to use some of its Medicaid funding for specific services that keep people in the community. However, it can be confusing to sort out which services a person may be eligible for and whether there are waiting lists and other barriers such as limits on the duration and types of services.



TIP

Some states use Medicaid waivers to allow recipients to enroll in assisted-living facilities. There may be restrictions, however — for example, requiring the recipient to pay for room and board with their own resources, or covering only certain services — and not all assisted-living facilities accept Medicaid. In January 2014, the Centers for Medicare & Medicaid Services issued a rule that strengthened community-living options for people on Medicaid by affirming that states can include assisted-living facilities as part of their home- and community-based services. The rule provides a transition period for states to ensure that standards are

met. Most assisted-living facilities aren't set up to provide extensive medical services. You can check for your state's program at www.payingforseniorcare.com/medicaid-waivers/assisted-living.html.

The availability and quality of these services varies considerably by location. Some states have robust home- and community-based programs and strong leadership; others do not. Variations also result from the state's population and income characteristics, the types of providers in the state, and the state's spending priorities. Many states have waiting lists for waiver programs.



TIP

Aging and Disability Resource Centers (ADRCs) can help with referrals to appropriate programs. Operated by the U.S. Administration for Community Living, they are intended to be one-stop shopping for referrals to long-term care services. For the ADRC in your area, contact Eldercare Locator at 1-800-677-1186 or go to <https://eldercare.acl.gov/Public/Index.aspx>.

Medicaid managed long-term care

Many states are now setting up managed long-term care programs to provide better coordination of services, more efficient program administration, better monitoring of quality, and (it is hoped) reduced costs. These programs are run by private companies under contract to the state that typically receive a per-member, per-month fee for care. In some states, some groups of people who have been receiving long-term services and supports are being moved into managed long-term care programs, and newly eligible individuals will start out in this kind of plan. Some states offer a choice of managed-care plans, while others do not.

These programs are evolving, and their characteristics vary by the length of time the program has been in operation, the population included, the types of services provided, program oversight, and the number of plans allowed within a state. Proponents claim that managed long-term care programs provide better integration of physical and behavioral health. Critics worry that managed long-term care plans will avoid enrolling the sickest and most vulnerable people or will fail to provide the extensive and costly care they need. Vigilant monitoring is needed to ensure that plans meet their obligations to all clients.

Depending on the competition among plans within an area, people eligible for Medicaid long-term care services can choose from several plans. Here are some questions to ask:

- » Will someone come to the home to assess the person's needs?
- » Will the person and family be able to participate in the development of the care plan and raise concerns?
- » If a family member is involved in care, will that person's needs for training and support be evaluated?
- » Will the same aide who has been caring for the person be allowed to stay on?
- » Is there a number to call when problems arise?
- » How are complaints or grievances resolved?
- » How does the person change plans?

In 2016, federal regulations added several Medicaid managed-care requirements and protections, including new rules applying to managed long-term care. These rules required states to establish enrollee support systems to provide independent counseling and information; standards for identifying individuals needing long-term care and developing their service plans; and network adequacy standards for plans' long-term care providers. More information is available here: files.kff.org/attachment/CMSs-Final-Rule-on-Medicaid-Managed-Care.



TIP

To keep informed about Medicaid managed-care plans in your community, contact the state's Medicaid office, the state's long-term care ombudsman (who investigates complaints), or a legal-aid organization that advocates for low-income people. Some states have set up special ombudsmen for Medicaid managed long-term care. You can find the ombudsman office in your state on the map at theconsumervoice.org/get_help.

- » Managing your own finances
- » Creating wills and trusts
- » Understanding probate

Chapter 8

Financial Matters: Money Management and Wills

In many families, money is a taboo topic. Talking about bank accounts or wills happens only when a crisis occurs. All too often, when a person dies, he doesn't even leave a will to guide the heirs. "Why make a will," some people reason, "when it will be expensive and complicated? My family will know what I want." And predictably, conflict and confusion ensue.



REMEMBER

Wills are only one of the legal and financial instruments that should be discussed, created, and periodically reviewed as part of a future care plan. Knowing how to deal with an older person's funds is essential for handling home care or assisted-living expenses. This chapter reviews general reasons for the primary legal documents and suggests some points to consider. However, it doesn't substitute for the advice of an experienced attorney or financial adviser (or both).

Managing Money

Understanding how to manage money is one of the most important skills we can acquire and pass on to our children. Yet it's one of the least-taught skills. Some people never think about money, and some people think about nothing else. But most of us get some basic introduction to financial management that serves well enough in ordinary times. Illness or aging, however, can create special situations that challenge our usual routines. This chapter describes some of those challenges. One is loss of control over one's money (or fear of that happening). For others, it is the daunting responsibility of taking charge of someone's financial affairs when they were shielded from money problems as they grew up.

Giving up control of money matters is often difficult for an older person, just as it is hard to give up driving. You may view losing any control over your finances as the beginning of the end of your independence. Because financial matters are so vital to aging comfortably and can be so difficult to manage, however, passing part of the control over to a trusted person not only makes sense but is also imperative in certain situations.

Right now, before a crisis, talk to your children or trusted adviser about the options for managing money should illness occur. Two basic options allow for shared control: a joint bank account or a financial power of attorney. The two options can be combined. I delve into the logistics of each option in the following sections.

Opening joint bank accounts

When you are no longer able to control spending or keep track of money coming in and out, it may be in everyone's best interest to have a shared bank account with a trusted family member responsible for managing it. But many older people have had their own bank accounts for decades, possibly a joint account shared with a spouse, and giving up some or all control to a child or other relative can be hard. If you're thinking of opening a new joint bank account, there are pros and cons to consider. As with other financial and legal matters, check with a professional.

» In most joint bank accounts, with a right of survivorship, there is no "my money" and "your money." Two people have

access to the account in its entirety, no matter which one earned or deposited the money. One person can withdraw the entire amount for any purpose without notifying the other owner.

- » Most joint accounts are set up so that if one person on the joint account dies, the entire account passes to the second person. But in certain states, this presumption can be challenged. The joint amount of money in the account is not included in the person's estate to be divided among the heirs. If the amount in the account is substantial, other family members may object. Even if the amount is small, other heirs may see this uneven distribution of assets as unfair. There may be income and inheritance tax implications as well.
- » An alternative but little-used option for a bank account is a *multipartty account without a right of survivorship*, sometimes called a *convenience account*. The account is held by a primary person, with a cosigner. In this type of account, the cosigner has the authority to make deposits and withdrawals, but if the primary person dies, the remainder of the account goes into the estate and does not pass to the cosigner. Although banking laws permit these accounts, many banks do not encourage their use, possibly because they require extra training of staff and monitoring. Still, if this seems a good option, talk to a banker about it.



WARNING

Adding another person to a bank account can have implications for future Medicaid eligibility. The account can be considered a transfer of assets at less than fair market value. If this transfer happens within five years of an application to Medicaid, the primary account holder will be penalized according to Medicaid look-back rules.



WARNING

Obviously, setting up a joint bank account should be done only with someone you trust completely. Even so, it may be prudent to keep only the minimum amount necessary to pay bills and avoid bank fees that may apply to a minimum balance. A large amount of cash sitting in a bank account can turn out to be an “attractive nuisance.” This term is more commonly used to describe something on a property, like an open pipe, that a child may find both dangerous and appealing. If the joint owner of the account takes out money for personal use, even with all the best intentions of repaying the money, there's always the possibility that he won't

be able to fulfill that promise. The annals of elder abuse are filled with stories of relatives, household help, and new “friends” who have taken advantage of a trusting older adult to enrich themselves or to pay themselves for taking care of an older person when that was never part of the agreement. Best not to put temptation into the picture.

A key concept when someone has access to another’s money is *fiduciary duty*, which occurs when one person depends on another to act in her best interest. The responsible person has a duty of loyalty to act only for the other person’s benefit, to act with good faith in furthering the other person’s interests, and to disclose all relevant information. Anyone taking on the responsibility of a joint bank account should be reminded about these ethical and legal requirements.



TIP

Consider drawing up an agreement that states the sources of money to be deposited into the account (such as Social Security, pension, and family contributions), how it will be spent (such as rent or mortgage, household expenses, medical bills, and household help), and what should happen to the balance if one party dies. This document is not legally binding but makes clear to both people (and to the rest of the family) how the joint account is intended to be used. The agreement may need to be changed if circumstances change.

Granting financial powers of attorney

If you need to step in to help take care of an older person’s finances, an alternative to holding a joint bank account is receiving financial power of attorney. Two types of financial power of attorney are available: conventional and durable.

Conventional financial power of attorney

Conventional financial power of attorney is granted by a document, signed by one person, giving another person permission to take care of different kinds of financial affairs, such as signing checks, paying a contractor for home repairs, handling bank accounts, and taking care of other tasks. The power of attorney may be limited to specific tasks, such as paying monthly bills, or it may be general and all-encompassing (allowing everything including selling property and assets like stocks, filing taxes, and managing a retirement account).

Depending on state laws, some powers can't be assigned to another person. Those include the power to make, amend, or revoke a will or change insurance beneficiaries.

The person signing the document is known as the *principal*, and the person who is designated to act in the principal's name is called the *agent* or *attorney-in-fact*. Unless specifically stated, a power of attorney goes into effect right away. But the principal can set it to expire on a certain date, and the principal can revoke the power of attorney at any time. Furthermore, conventional power of attorney ends if the principal becomes legally incapacitated, which means she is unable to understand choices and make decisions.



TIP

To avoid personal liability, agents should sign a check or any document, for example, as John Brown (your name), attorney-in-fact for Mary Brown (your mother).

Durable financial power of attorney

An alternative to a conventional financial power of attorney, which ends when the principal (the person who signed away some powers) becomes legally incompetent, is a *durable financial power of attorney*, which continues even if the person becomes incapacitated. Therefore, durable power of attorney lets the agent remain in control of certain financial and legal matters even if the principal is no longer able to understand the decision to be made or its implications. For example, a person with advanced dementia would be considered incapacitated, as would someone in a coma. All states recognize some form of durable power of attorney, but the specifics vary.

A version of durable power of attorney is called a *springing durable power of attorney*. It sets conditions under which the durable power of attorney “springs,” or goes, into effect — for example, when a doctor certifies that the person has become incapacitated. The springing durable power of attorney may be more acceptable to an older person and avoids the lengthy, costly, and emotionally difficult process of guardianship. However, the springing durable power of attorney must be very clear about what counts as the springing event so the principal, agent, and other third parties who need to rely on the power of attorney can easily determine when the principal intended the agent to take over. Without clarity, a court may have to decide. This would negate one of the benefits of having a power of attorney, which is that financial and legal matters can be handled without going to court.



TIP

Even if you have a durable power of attorney in a form approved by your state, your bank or other financial institution may require its own form. Even the Social Security Administration requires its own version of a power of attorney. Be sure to ask your financial institutions whether they honor the standard form or require their own.

The fiduciary duty applies to durable power of attorney as it does to joint bank accounts (discussed earlier in this chapter). Agents are required to act in the person's best interests, maintain accurate records, and avoid any conflict of interest. Most people are not well versed in the fiduciary responsibilities that accompany being named an agent in a durable power of attorney. The same temptations that can occur in a joint bank account are present with a durable power of attorney, and here the stakes may be even higher. Therefore, all financial actions taken on behalf of the person who is incapacitated must be transparent, and all family members involved in the care of the older person must be apprised of significant outlays. Disagreements may arise, but better to have them resolved early rather than cascade into serious trouble.



REMEMBER

A financial power of attorney does not extend to making health-care decisions. That requires a separate document, which can be called by different names but is usually termed a *healthcare proxy* or a *durable power of attorney for healthcare*. It's discussed in Chapter 11.

Where There's a Will . . .

If you have any money, property, family heirlooms, or just personal treasures, or if you have children or other dependents who will need a new guardian after your death, you need a will. A will ensures, as much as possible, that your wishes are followed. One way to convince a resistant older person of the importance of creating a will is to make one yourself or to remind the person that you went through the process, and although it wasn't easy, it was a relief to have completed it.

Many people believe that if you die without a will, your family will automatically divide up your property. Not exactly. A person who dies without a will is legally *intestate* (defined, simply, as not having a will). In that case, state law operating through a probate court determines how the property will be divided, often leading

to outcomes that the person would never have wanted. Blood relatives will likely be favored over domestic partners. Children will be treated equally, even if one of them has been estranged from the parent for years. Stepchildren may not be included, even though they are well loved. Such unwanted outcomes can be avoided through the creation of a valid will.

Many people overestimate the monetary value of their possessions but underestimate their sentimental value to family members. An older person may say, “That old painting? Who would want that?” The answer may be, “A lot of your children or grandchildren who remember it hanging on your wall when they came to visit.” Or that item may be promised to more than one person. Your parent may say, “When I’m gone, that painting is going to be yours. It’s worth a lot of money.” Whether the painting has financial value or not, promising it to several people is bound to create conflict.



REMEMBER

Instructions about burial or cremation and funeral or memorial service plans should not be put in a will. A will is generally read several days or weeks after death, when it’s too late to honor the person’s wishes. Specific directions about those logistics should be put in a separate document and shared openly with close family or, if not, opened at death. It is best to alert family members about this document to avoid conflicts. AARP has helpful guidance on planning funerals at www.aarp.org/home-family/friends-family/info-2017/funeral-planning-tips-fd.html.

Preparing a will is very important, and it will be a valued document when an older person passes. Look at the following sections to find out how to get started and what types of wills are available.



TIP

As early as possible, consult an attorney who can guide you through the process of taking inventory of your assets, determining what kind of will best suits your situation, choosing the executor, considering provisions to include, and finalizing the will.

Taking inventory of your assets

In considering a will (and for estate planning in general), start by making a list of assets to be distributed and indicating whether they are jointly held or have a designated beneficiary, including:

- » Liquid assets (things that can quickly be turned into cash), such as bank accounts (checking and savings), certificates of deposit, savings bonds, and money market funds.

- » Fixed assets, such as a home or other real estate.
- » Certificates of deposit that are payable to a named person on death.
- » Retirement accounts, such as 401(k) plans, IRAs, Keogh accounts, and pensions. These accounts should be included in the inventory whether or not they have a designated beneficiary. If there is no beneficiary, they go into the probate estate. If there is a designated beneficiary, they are not distributed by the will or the probate estate.
- » Stock or investment accounts.
- » Transfer-on-death stock accounts, which are payable to a named beneficiary.
- » Valuable personal items such as jewelry, antiques, and artwork (items with only sentimental value can be kept in a separate list).



TIP

Community property is the law in nine states (Arizona, California, Idaho, Louisiana, Nevada, New Mexico, Texas, Washington, and Wisconsin). Alaska recognizes community property if both spouses agree to divide their assets in this way. This means that property acquired during a marriage is shared equally by a married couple regardless of who purchased the property or earned the money. Only the share owned by one person can be distributed in a will. This may call for some Solomonic decisions, but it can be addressed in a will by a spouse giving his or her half of the community property to the surviving spouse.

Considering types of wills

According to the American Bar Association, there are several types of wills:

- » For an uncomplicated estate, a *simple will* provides for the outright distribution of assets.
- » A *pour-over will* assigns some assets to a trust that has already been established.
- » A *holographic will* is handwritten but not witnessed. About half the states recognize this kind of will, but it's not a preferred option.
- » An *oral will* is spoken but not written down. Very few states recognize this kind of will, and then only in cases of final illness. It, too, is not a good option.

Choosing the executor

Choosing the *executor* — the person responsible for making sure that the instructions in the will are followed — is an important step. Being named as an executor is not an honorary title; it involves a considerable amount of time-consuming work. The executor must create an accurate accounting of assets to be distributed, find all debts that need to be paid, and resolve tax questions. Consultants such as accountants and attorneys may need to be hired. Unhappy relatives may need to be placated. The ideal executor is a person who is adept at understanding finances, detail-oriented, and even-tempered.

If this job description fits someone in the family, then that person would be a good choice. If not, then look outside the family for a trusted friend or professional. A professional will expect to be paid, and fees may be a flat amount or a percentage of the estate.

The person named as executor should be willing to take on that job, because if the person declines, a court will name another executor and it may be someone you would not choose. You should name an alternate in the will in case your first choice to be executor cannot serve.

Taking the final steps

After you've made these decisions about the will, the American Bar Association says there are several more steps to take:

1. **Execute the will.**

This step means having witnesses present as you sign the will. All states require at least two witnesses as proof that the will is valid — that is, the person signing the will knew what he was doing. Witnesses' signatures must be notarized. The witnesses should not be the executor or people named in the will to receive any gifts (even of modest value). Usually the witnesses are employees in an attorney's office, who do this every day.

2. **Decide where to keep the will.**

You should have only one signed original that you keep in a safe place. The attorney who drafts the will may or may not take the responsibility of storing it for you. Family members who need to know about its contents can be given unsigned copies and told where the original is stored.



WARNING

Putting the original will in a safe deposit box is not a good idea, because upon death, some banks restrict access to safe deposit boxes until there is a court order that it can be opened, which may not happen quickly.

3. **Review the will at regular intervals.**

Creating a will is important for all adults. But people who create a will at one stage of their lives (for example, when they have young children) may forget about the will as the children grow up and have children of their own. In that case, almost everything has changed in their lives, but the same will exists. Any major life-changing event — divorce, death of a family member named in the will, remarriage, birth or adoption of a child, sale of a business, moving to a new state, onset of a life-threatening illness — is a reason to review a will and make appropriate changes. In the case of moving to a new state, you need to make sure that the new location will honor your will executed in another state, or you may need to draw up a new will. Your priorities may be the same or they may be different. In either event, the will should be kept up-to-date.

Settling the Estate with Probate

Probate is a word that is often preceded in advice columns by the word *avoiding*. What exactly is probate and why do so many people want you to avoid it?

Probate is the process of settling an estate. It is also the name of the state court that handles wills and estates, among other responsibilities. The probate court determines the validity of the will, reviews the executor's inventory of assets and list of creditors, and determines what debts should be paid and what taxes are owed. After all these obligations are taken care of, the remainder of the estate is distributed according to the terms of the will. Failing to write a will is not a good way to avoid probate because a court will be involved in settling your estate anyway.



REMEMBER

Probate addresses only certain assets in an estate, mainly assets that are not designated to go to a named beneficiary. Probate assets typically include a home, other property owned solely by the person, artwork and other personal items, and bank accounts

held only in the person's name. Assets that normally don't pass through probate include joint bank accounts, pay-on-death accounts, life-insurance policies, retirement accounts, and other assets with a named beneficiary. Property held in trusts does not normally pass through probate.

Why are people so eager to avoid probate?

- » **It can be costly.** It involves court fees, attorney fees, and other fees, which can add up. Some costs are set; others may depend on a percentage of the estate's value.
- » **It can take time.** Heirs eager to have closure or get their share of the estate may be frustrated by the slow but steady process of probate. Time has to be allowed for creditors to be notified and to come forward, ownership of assets to be determined, and all the other details that must be resolved and can complicate settling an estate. It can take 9 to 12 months to close a larger or complicated estate.

Many states have streamlined the probate process, allowing spouses and minor children to get the money they need to live on without waiting for the entire estate to be settled. Other states have a simple probate process for smaller estates that can be closed in weeks at reduced costs.

There are different kinds of probate, depending on state law:

- » **Small-estate:** The simplest form of probate that can be used (but not in every state), for estates ranging in value from \$1,000 to \$10,000, depending on state law.
- » **Unsupervised or independent:** A reasonably simple and less expensive form of probate used when the estate is more than the value of a "small estate" but doesn't require a lot of court supervision. It can be requested when all the beneficiaries agree (and consent, if the will requires consent).
- » **Supervised:** Typically applied to large estates and wills with complicated provisions, with the court playing a major role in approving every action. Supervised probate is used if the will is contested, someone named in the will requests it, or the court is concerned about the executor's abilities.

**REMEMBER**

If the will involves property in more than one state, the probate court in each state will be involved, adding to the costs.

One of the best ways to avoid the costs and delays of probate is to have a good estate plan in place. If the will is up-to-date and properly prepared, all the provisions are made in clear simple language, and the beneficiaries are advised about what they can expect (and won't be getting), chances are that the will can be probated at minimum cost and with minimum delays. The more money that is involved and the more people who will stand to gain (or lose) from the will, the more likely it is that there will be complications. Even so, planning can reduce some of the potential problems.

- » Understanding special medical needs you may have
- » Finding the right doctors
- » Making your way around hospitals
- » Managing medications

Chapter 9

Choosing Good Medical Care

The good news is that Americans are living longer, and many older adults are in good or excellent health. How can you get the best medical care to stay healthy? How do you manage prescription and over-the-counter medications? And what should you do if you require a hospital stay? This chapter covers all those topics.

I also discuss geriatric care. The term covers a wide spectrum of necessary services, but most often it refers to managing the medical side of aging — from doctors to hospitals to medications.

One question commonly asked is this: “Who is in charge of managing the medical side of care?” That answer used to be simple: “The doctor who has treated my family for years.” In today’s complex and constantly evolving healthcare system, the answer is more likely to be your primary care provider or perhaps a specialist, such as your cardiologist. But sometimes it may seem that nobody is in charge — and having someone in charge is important. In this chapter, I help you find the right medical quarterback.



The information in this chapter is intended to provide general information and does not substitute for advice from a qualified physician or other healthcare professional.

Checking on the Special Medical Needs of Older Adults

Many factors contribute to length of life, but in general women live longer than men do. According to the U.S. Centers for Disease Control and Prevention (CDC), life expectancy at age 65 for both women and men is on average 19.3 years. For men, it's a little less — 18 years — and for women, a little longer — 20.5 years. Of course, these ages are averages, and everyone knows 90- and 100-year-old men who are doing fine and women who have died at much younger ages.

Increased longevity has increased the burden of chronic disease. In earlier days, people died from acute (rapid onset) conditions like pneumonia, bacterial infections, or accidents. Although these causes of death still exist, the more common conditions are chronic — that is, they last a long time and can be treated but typically can't be cured.

Identifying common chronic conditions

According to the CDC, in 2020 six in ten adults have a chronic disease and four in ten have two or more chronic diseases. Chronic diseases and conditions — such as heart disease, stroke, cancer, type 2 diabetes, obesity, chronic lung or kidney disease, and Alzheimer's and other dementias — are among the most common and costly of all health problems. Not all are preventable, but smoking, poor nutrition, lack of exercise, and overuse of alcohol are common risk factors. Of these conditions heart disease, cancer, and lower respiratory diseases are the leading causes of death.

Arthritis is the most common cause of disability. Of the 54 million adults with doctor-diagnosed arthritis, more than 23 million say that arthritis causes trouble with their usual activities. Diabetes is the leading cause of kidney failure, lower-limb amputations other than those caused by injury, and new cases of blindness among adults.

Alzheimer's disease is the fifth leading cause of death for people over the age of 65. (A typical list includes accidents, which puts Alzheimer's at number 6.) This statistic may be an underestimate because the immediate cause of death may be recorded as some other condition. More than 5 million people have this disease or another dementia. It is probably the most feared chronic disease, more so than cancer.

Other chronic conditions include:

- » **Hypertension:** Hypertension (high blood pressure) is the most prevalent condition among older adults, affecting 71 percent of people over 65. Untreated or poorly controlled hypertension can lead to strokes.
- » **Dyslipidemia:** Too much LDL (low-density lipoprotein) or "bad" cholesterol, a condition known as *dyslipidemia*, affects 45 percent of older adults and is associated with blood clots and heart disease.
- » **Lung disease:** Lung conditions, such as chronic obstructive pulmonary disease (COPD), emphysema, or chronic bronchitis, affect 14 percent of older women and 11 percent of older men. Not surprisingly, COPD is three times higher among current smokers compared with those who have never smoked.
- » **Osteoporosis:** Osteoporosis (thinning of bones) is more common among older women (26 percent) than men (4 percent). Osteoporosis increases the risk of fractures after a fall.
- » **Vision problems:** Cataracts are the most common vision problem among older adults, affecting 41 percent. People with diabetes are more likely to have cataracts and glaucoma than nondiabetics.
- » **Incontinence:** Over a third of older adults experience urinary incontinence, and the prevalence is higher among women (47 percent) than men (18 percent).
- » **Mental health problems:** Mental health problems — depression, anxiety, obsessive compulsive disorder (OCD, which manifests in hoarding), and others — add to the burden of physical conditions.



TIP

Many of the chronic conditions that older adults experience are accompanied by pain. Chronic pain limits function and well-being. But overprescription and overuse of pain medications can lead to serious side effects and dependence. Talk to your doctor about ways to manage pain that are less risky than opioids such as fentanyl and morphine and many brand-name drugs. If you're using these drugs, be sure to keep them securely stored, away from children and others who may be tempted to use or sell them. The American Geriatrics Society's Health in Aging website has helpful information about non-narcotic ways to manage pain. Go to www.healthinaging.org/aging-and-health-a-to-z/topic:pain-management/info:care-and-treatment/.

Dealing with multiple ailments

Approximately one in four Americans has at least two chronic conditions, but the burden of chronic disease is even higher in older adults. Among Original Medicare beneficiaries, over two-thirds have two or more chronic conditions. About one in seven have six or more, and this group accounts for almost half of total Medicare spending. Older adults with several chronic conditions are known in medical jargon as *multimorbid*.

Chronic conditions are not only difficult to manage on their own; they also frequently lead to loss of function. A person with two arthritic knees or hips has a hard time getting around without pain, and immobility leads to other problems. Strokes can affect speech and movement. Heart disease and COPD may limit activity. And memory and behavior problems associated with Alzheimer's disease and other dementias that worsen over time create difficult situations in which the older person's personality, judgment, and ability to communicate undergo major changes.



REMEMBER

Preventive measures, such as those to reduce the risk of falls, can help maintain good health. These measures are discussed in Chapter 3. The benefits of good nutrition, exercise, social activity, and moderation in alcohol use are well known. Genetics, we are finding out, plays a part as well, although how genes interact with other factors is still unclear.



REMEMBER

Whatever the combination of factors that apply to a specific person, it is essential to have good medical care — that is, care that considers the way aging affects the body and the difference in medication absorption and side effects between older adults and the younger populations on which most drugs were tested. When

looking for a doctor, consider technical competence as well as the professional's ability to focus on the whole person, not just body parts and disease. I give more guidance on finding a good doctor in the following section.

Finding the Right Specialist to Manage Care

As you age, you may stay with your current doctor. Or you may seek a geriatrician or gerontologist — someone who specializes in aging. What is the difference between a geriatrician and a gerontologist?

- » *Geriatrics* is a medical subspecialty. *Geriatricians* are physicians, primarily internal medicine doctors, who have taken additional training that focuses on the diseases of aging and their treatments. They have been certified by the American Board of Internal Medicine to practice geriatric medicine.
- » *Gerontology* is a multidisciplinary study of the mental, physical, environmental, and social aspects of aging. *Gerontologists* do research, teach aging in universities, participate in organizational planning and policy, and contribute to the broad knowledge about the impact of aging on individuals and society.

Perhaps the simplest distinction is this: While both geriatricians and gerontologists are called *doctor*, a geriatrician is an MD or a DO (doctor of osteopathy) and a gerontologist is usually a PhD. An MD can prescribe medications; a gerontologist can't. Geriatricians see patients individually, while gerontologists generally do not, although they may work in settings like nursing homes or government agencies to advise on practice and policies.

Considering the need for a geriatrician

Is it essential for an older adult to be treated by a geriatrician? No. Many internists (internal medicine doctors) and family physicians provide excellent primary care for older adults. Although they may not have advanced training, they have the benefit of experience. Among their patients are undoubtedly many older

adults, and experienced doctors have learned that older adults may need more time during office visits and react differently to medications than their younger patients.

The American Geriatrics Society recommends that a geriatrician should be consulted in the following circumstances:

- » An older person's condition causes considerable impairment and frailty. These patients tend to be over the age of 75 and coping with several diseases and disabilities, including cognitive (mental) problems.
- » Family members and friends are feeling considerable stress and strain as caregivers.

Many older people want to stick with a doctor they have known for years. (But the doctor, of course, is aging too, which may be something to consider.) If you have a good relationship with a doctor and the care needed is not highly specialized, then you have no reason to make a change.



REMEMBER

Be sure to be particularly observant about symptoms that may indicate a change in your condition, or a medication side effect that may be related to a person's age. If your regular doctor doesn't take questions or observations about memory or behavior changes seriously, this may be a sign that it's time for a change. Family members and sometimes older people themselves are often the best reporters of changes that may indicate something serious. Maybe it's a side effect of a medication (even one that has been taken for a long time) or a urinary tract infection. Maybe it's a sign of depression. Maybe it's a sign of early dementia. Geriatricians can do comprehensive evaluations of these worrisome but often nonspecific reports and can recommend further testing if necessary.



TIP

If your regular doctor refers you to a specialist, ask specifically about that person's experience and qualifications for treating older adults.

Finding a geriatrician

If, for whatever reason, you are looking for a new doctor, I recommend finding a qualified geriatrician. But it's not as easy as it sounds, because there's a shortage of geriatricians. Some established geriatricians aren't taking new patients, or there may be a

long wait for an initial visit. Many geriatricians see patients only part of their time because they are involved in training programs.

Here are some suggestions for finding a geriatrician:



WARNING

» **Check online.** Members of the American Geriatrics Society (geriatricians, geriatric nurse practitioners, and geriatric physician assistants) who want to participate in its referral program are listed at www.healthinaging.org/find-a-geriatrics-healthcare-professional. The society does not endorse individual providers, but all the physicians listed are either Board Certified in Geriatric Medicine (internists) or have a Certificate of Added Qualifications in Geriatric Medicine (family physicians).

Some commercial websites also offer to help you find a geriatrician. These lists can be useful, but they are not comprehensive, and the doctors have probably paid to be listed.

» **Contact a hospital.** Contact a hospital or academic medical center in your area. Its “Find a Physician” lists provide names and qualifications.

» **Use Medicare resources.** If you or your parent is a member of a Medicare Advantage plan, look at the list of providers in the plan to find geriatricians.

» **Ask around.** Use the old-fashioned method of asking friends and family. Ask specific questions about how efficiently the office is run, whether the doctor has good communication skills with older adults, whether he has emergency backup if needed, and any other questions that may apply. Is the office easily accessible, even for a wheelchair? Are the staff pleasant and responsive to older people? If you have to be admitted to a hospital, which one will it be? Does the doctor make hospital and home visits?

Navigating Hospitals

Nobody likes having to go to the hospital, but it is a necessary factor in some medical equations. When a hospital stay truly is necessary, keep in mind certain points to help the experience go more smoothly. The next sections discuss these areas.

Where to go for emergencies and non-emergencies

Emergency departments (EDs) are often the first stage of a hospital stay. Most people still call them *ERs* for emergency room, but the formal term is ED. Whatever the title, they are usually busy, chaotic, and difficult environments for anyone, but particularly for an older person. Yet all too often they are the default solution for a problem instead of a well-considered decision.

Emergency departments

EDs are designed to treat real emergencies — difficulty breathing, choking, loss of consciousness, severe pain — not for problems that can be treated at home or at an urgent care center and followed up with a doctor visit in the next day or two. Of course, no one wants to make a mistake by discounting the seriousness of a medical complaint, but calling the doctor's office or your health plan's nurse hotline to get a professional opinion about the urgency of the complaint can help you avoid unnecessary trips to the ED.



WARNING

If the person answering the phone at the doctor's office doesn't ask questions or offer any suggestions but just says, "Take your mother to the emergency room," it is likely a bad sign about the care being provided. And if the default recording on evenings and weekends is "If this is an emergency, hang up and call 911," ask the doctor at a regular visit what counts as an emergency. Or suggest a different way to handle these calls.



TIP

Some hospitals have created special EDs for older adults who are not sick enough to be admitted to the hospital but are not ready to go home. These special units are quieter, staffed by nurses and others used to working with older adults, and more comfortable than the typical ED. Patients can stay in these settings while tests are run, medications are given, they're observed for side effects, and until someone can provide a safe ride home. Ask whether your local hospital has this kind of special ED.

Urgent care centers

An alternative to an ED visit is an urgent care center. Urgent care centers are walk-in sites appropriate for situations such as a fever, a sore throat, or a persistent bad cold. Staff (often ED-trained doctors) can evaluate the problem, take X-rays, and prescribe medications. If they feel that an ED visit is required,

they can call an ambulance. If you go to an urgent care center, make sure to inform your regular doctor about what happened and what was recommended.

Urgent care centers can be a very convenient and useful option. The number of urgent care centers in many parts of the country has been increasing. They are often less expensive than an ED and may be located nearer to you. The waiting time is also usually shorter than in an ED, and these centers take most insurance plans. Your health plan may not consider an urgent care center near you as part of its network, so it's a good idea to find out now just in case you need one later.

Another option is a full-service ED that offers more than an urgent care center but is not located at the hospital, although it may be part of a health system network. This may be an option if there is one in your area. They can provide a wide range of services and arrange transportation to a hospital should that be necessary. Finding out whether your insurance will cover these visits is important here too.

Being admitted to the hospital

A hospital stay, especially a long one or one that involves being in an intensive care unit (ICU), is certainly upsetting for everyone, and infection is an ever-present risk. You can become disoriented by the noise, lights, constant questioning, and different people coming in and out of the room. Long waits in cold corridors for X-rays and other tests add to the misery.

Patients may not get enough to eat, especially if doctors order them to fast before procedures. Getting a full night's sleep is next to impossible. Patients are often prescribed painkillers or other medications that can leave them confused or even delirious, especially in the unfamiliar surroundings of a hospital. Extended bed rest can weaken patients' muscles and bones. Even with kind and caring staff explaining what is happening (not always the case), a hospital stay is almost guaranteed to be unpleasant at best and debilitating at worst.



TIP

Some hospitals have special units for older people called Acute Care for Elders (ACE) units. They are staffed by a specially trained interdisciplinary team, which can include geriatricians, advanced practice nurses, social workers, pharmacists, and physical therapists. The team assesses patients daily, and nurses are given an

increased level of independence and accountability. These units have been shown to shorten length of stay and result in lower cost while maintaining patients' functional abilities. If hospitalization is necessary, ask whether your hospital has an ACE.



WARNING

If you have been given a bed on a regular hospital floor, make sure you have formally been admitted as an inpatient. If the doctor or nurse isn't sure, ask the admitting office. The hospital may claim that you were under observation, even though you received the same services as everyone else. Because you haven't been formally admitted, Medicare will not consider this stay as a Part A (hospital) benefit, for which you pay only an inpatient deductible, but as a Part B (outpatient) benefit. Your portion of the bill may be higher and will include costs for lab tests, X-rays, medications, and other things that would typically be covered under Part A. And if you go to a rehab program in a nursing facility after this stay, you will have to pay privately since you will technically not have had the required three-day inpatient hospital stay required by Medicare. Legislation has been proposed to change Medicare rules on observation stays, but the outcome is pending. For now, make sure you ask whether you are admitted or on observation. You're supposed to receive a notice called a MOON (Medicare Out-patient Observation Notice), but that may not happen. There is no way to appeal the hospital's decision to place you on observation, but you can register a complaint with the hospital administration and with Medicare. The Center for Medicare Advocacy has advice at www.medicareadvocacy.org/medicare-hospital-outpatient-observation-status-toolkit/.



TIP

Your primary doctor may or may not visit you in the hospital. It would be good to ask at a regular visit whether your primary doctor visits patients when they are hospitalized and which hospitals they visit. Increasingly, hospital care is managed by specialists called *hospitalists*. These doctors are trained in critical care medicine and are skilled at handling medical crises that happen to seriously ill patients. They generally work in teams so someone from the team is available at all hours of the day and night and on weekends. This also means that patients may not see the same staff every day. Hospitalists are employed by the hospital or belong to a group practice that is under contract to the hospital. They do not generally see patients after discharge, although some groups do have physicians who work both in the hospital and in the community.

Planning for a hospital stay

Hospitalization for an elective (planned) surgery for an older adult is in theory easier than an admission through the ED because you have time to get ready. But there's a lot to think about, no matter the reason for the surgery.



REMEMBER

All surgery has risks, and you want to be sure that the potential benefits are worth the risks. Someone's age alone should not be a reason to decide against surgery, but a very frail person in poor health and perhaps with moderate or advanced dementia is probably not a good candidate for surgery. Be sure to ask about and consider alternatives.

The surgeon is generally a specialist recommended by the geriatrician or the primary care physician. An orthopedic surgeon replaces hips and knees, a cardiac surgeon replaces valves and inserts pacemakers and stents, and a renal surgeon takes care of kidney problems. They are experts in their specific area, but you need someone to look after the whole person, and that is the geriatrician or primary care doctor.



REMEMBER

It is important that these doctors talk to each other, not just in the initial referral but also as the surgery is approaching and definitely afterward. The time spent in the hospital may be very short, which is a good thing, but it also means that the recovery time needed at home is longer, and care must be taken to avoid complications. Older people react differently to anesthesia, may experience more pain, and take longer to recover than younger people undergoing similar surgery.



TIP

Many hospitals will inform primary care doctors when one of their patients is admitted, but this doesn't always happen. If you're the patient, ask a family member to call your regular doctor's office to give that information and the name and contact information of the hospital doctor in charge of your care. And ask the hospital doctor — probably a hospitalist — to contact your regular doctor to discuss your diagnosis and treatment. This is especially important as you get ready to be discharged because you will need follow-up at home. Both hospital and primary care doctors are busy and may need some reminders about making sure they both know the specifics of your care.

Because so many older adults are undergoing surgery, the American Geriatrics Society and the American College of Surgeons worked together to create a series of guidelines for surgical teams. These “best practice” guidelines are intended for surgeons, but they are also useful for the person undergoing surgery and family members. Here are some of the key points:

»» Talk to the surgeon about what to expect from the surgery:

- What are the treatment goals? Will the surgery fix the problem, or will there still be limitations?
- What kind of anesthesia will be used? Are there common side effects?
- How long will the surgery last? How long will the person be in the recovery room?
- How will pain be treated? Ask about alternatives to morphine and other opioid drugs to lessen the risk of dependence on them. But don't suffer in silence. Pain is debilitating and should be treated.
- Will there be physical limitations such as being able to climb stairs, get in and out of bed, and use the toilet? Even a generally successful surgery like hip replacement is always followed by a period of restrictions on mobility. Can the person follow instructions so the surgery is not undone by a fall or other accident?

»» Ask where you will go after surgery. You may expect and want to go home, but the surgeon may recommend a short stay of a few weeks in a rehabilitation program, probably in a nursing-home rehab unit. There you can recover more fully and get therapy to restore and improve function. Even that new hip takes time to get used to, especially if you have been in pain and not walking properly for some time before the surgery.

Some health plans have specific rehab programs in their network and going out of network will be costly. Even if you feel you have no choice, it is important to investigate the sites to see which ones best suit your needs. Location is important, of course, but quality matters too, so try to find out as much as you can about whether other patients with similar conditions have had good outcomes. The government website Nursing Home Compare at www.medicare.gov/nursinghomecompare/search.html has information on long-stay residents but not much on short-term rehab.

- » Ask about costs. Medicare or other insurance will cover some or all the surgeon's fees (but there will be a copayment) and the hospital fee. But the anesthesiologist will submit a separate bill. Review Medicare's policies at www.medicare.gov if you are in Original (fee-for-service) Medicare; if you are a member of a Medicare Advantage plan, ask the plan for details about costs. For Medicaid and other insurances, ask the case manager, usually a nurse in charge of planning your care after discharge.
- » Ask ahead about eligibility for some skilled nursing visits and possibly physical therapy at home after discharge from the hospital or rehab program. It will take some time to get used to being at home, and everyone can benefit from some extra help.
- » Make sure the surgeon is aware of any special problems, like depression or alcohol use that may affect responses to surgery or recovery. For a comprehensive list of the guidelines, go to www.nextstepincare.org/Caregiver_Home/Elective_Surgery.



TIP

A law called the CARE Act (Caregiver Advise, Record, Enable) has been enacted in 42 states and territories. This law, which AARP supports, is designed to ensure that family caregivers (as identified by the patient) are included in discussions about the post-discharge care plan, informed about the day of discharge, and given instructions about all medical tasks that need to be done at home, such as managing medications or caring for surgical wounds. If you're the patient, you should know that you will be asked to identify someone who can help you at home until you can manage on your own. And if you're the family caregiver, you should know that you do not have to agree to perform all the necessary tasks but that you can get help from the hospital staff to learn what needs to be done. Go to this video to see how the CARE Act works: <http://videos.aarp.org/detail/video/5793819744001/how-the-care-act-works-%E2%80%94aarp>. A map of states with CARE Act legislation as of June 2019 is at www.aarp.org/content/dam/aarp/ppi/2019/09/care-act-map.pdf.

Polypharmacy: Too Many Drugs?

More and more people take a lot of medications and vitamins, dietary supplements, herbal preparations, and other drugstore items that don't require a doctor's prescription. It's called *polypharmacy*.

Advertisements persuade people that a certain drug must be good for you. If it's new, it must be better. If it's sold without a prescription, it must be safe. If it's "natural," it must be better than something created from chemicals. If it's been around for years, like aspirin, it can't hurt you. For all these beliefs, the reality is this: Not exactly. Taking aspirin, for example, is sometimes used jokingly, as in "Take two aspirin and call me in the morning." But overdoses of aspirin can kill, and even nonlethal doses can cause stomach bleeding and other problems. Always check with your doctor.

With all these drug-promoting ideas in the culture, it may seem as though everyone follows the directions from the doctor, pharmacy, or package label very carefully. Not at all. People get into trouble when they take too many of the wrong medications or skip some that they should be taking and generally adopt a casual attitude about these powerful concoctions. According to the CDC, more than 700,000 ED visits every year are related to adverse drug events. And a growing epidemic of addiction to prescription medications is taking a toll on all ages across the United States.

People often don't tell doctors about everything they are taking and not taking. When the doctor asks, "Are you taking your medicines?" the answer is likely to be "Yes" when the reality is "Not so much." And the doctor may not ask whether you're taking any other medications. Even if the question is asked, people may answer with what they consider a truthful "No," because they don't realize that all the over-the-counter items are in fact medications, not harmless concoctions.

It's easy to get confused about medications. They come in brand names (the advertised versions) and generic preparations, which are cheaper but have harder names to remember. Hospitals have their own formularies (list of drugs they use), which may not be the same as the drugs used at home.

Using caution with certain drugs

Recognizing that certain drugs are potentially risky for older adults, the American Geriatrics Society periodically updates a list called the Beers Criteria for Potentially Inappropriate Medication Use in Older Adults. This list contains medications and types of medications that are "potentially inappropriate" for older

people and can be replaced with safer or more effective medications or nondrug remedies. Some drugs are listed to be used only with caution. The Beers list updated in 2019 is available at [www.pharmacytoday.org/article/S1042-0991\(19\)31235-6/pdf](http://www.pharmacytoday.org/article/S1042-0991(19)31235-6/pdf).

HealthinAging.org, an educational arm of the American Geriatrics Society, has prepared a list, viewable at www.healthinaging.org/files/documents/tipsheets/meds_to_avoid.pdf, of ten medications older adults should avoid or use with caution. For example, long-lasting nonsteroidal anti-inflammatory drugs (NSAIDs) used to reduce pain and inflammation can increase the risk of indigestion, ulcers, and bleeding, as well as increase blood pressure and make heart failure worse. Shorter-acting NSAIDs like ibuprofen are better choices. Other medications on the list are certain diabetes drugs as well as medications used for anxiety and insomnia.



REMEMBER

The Beers List and other similar lists are not the final word on whether a particular drug is right for you. The drugs on the list have been approved by the Federal Drug Administration, so they are marketed legally. But if you're taking one of these drugs or your doctor prescribes a new one, you need to review the choices and any alternatives. One of the drugs that the list says to avoid or use only with caution may in fact be the best choice for your specific condition. But unless you ask, you won't know why the doctor has recommended this drug rather than another one that seems to be less risky.

Getting medications right



REMEMBER

You can do many things to make sure you're taking the right medications at the right time in the right dose:

- » Keep an updated list of all your medications, prescription and OTC, and show it to every doctor at every appointment. Review the list at least once a year and certainly after a hospital stay.
- » Whenever a new drug is prescribed, ask why you should be taking it, what side effects to look out for, whether it interacts with any of the other drugs you're taking, and what to do if you miss a dose.
- » Read the label on the bottle. If the type is too small or the language too dense, ask the pharmacist for an easy-to-read version.

- » Follow the directions, and if you don't understand them, ask the doctor or the pharmacist. Sometimes medical professionals think that directions are clear ("Take this on an empty stomach") when they are not (what constitutes an empty stomach — two hours after eating? first thing in the morning?). Take the drug for as long as you've been told — not for a longer or shorter time.
- » Report any changes in your medical condition, which may be related to a new drug. If the reactions are serious, such as an extensive rash, difficulty breathing, or swelling in your throat, they count as emergencies. Call 911 or go the nearest ED.
- » Throw out any unused medications. Don't give them to anyone else, and don't take medications that were not prescribed for you.
- » Be especially careful to keep pain medications where they don't create an "attractive nuisance" for a child who may want to taste or drink them and where they aren't easily accessible to adults in the family, workers, or visitors.

- » Using a nursing home for short-stay rehabilitation or long-term stays
- » Selecting the right nursing home
- » Understanding residents' rights and responding to problems

Chapter 10

Understanding the Different Roles of Nursing Homes

Don't skip this chapter because you've always said, "I'll never put my mother in a nursing home!" or because you don't want to even think about this option for yourself. There is no denying that moving permanently to a nursing home is at the bottom of most people's want list.

Just to be clear: A nursing home is a long-term care facility that offers 24-hour room and board and healthcare services, including nursing care, rehabilitation therapies, and a range of other treatments and programs. Nursing homes increasingly have two types of services: short-term rehabilitation programs and long-stay units.

You may never need a nursing home. As I point out in other chapters, many people have other options for care at home and in the community. Still, you may need a nursing home for rehab programs, which can ease the transition from hospital to home. And for some people, particularly those with advanced dementia or complex medical needs, family care and home- and community-based services may be insufficient.

In this chapter, I discuss both short- and long-term stays in nursing homes, with the emphasis on long stays. I offer steps for selecting a nursing home. Finally, I provide information about residents' rights that are important after you've moved in.

Beginning with Nursing Home Basics

By choosing a nursing home for a long stay, rest assured that you aren't abandoning your parent or other relative. You'll need to remain involved at many levels to ensure that the person receives the most appropriate care, is respected as an individual, and is able to maintain the highest level of function possible and enjoys a good quality of life. Starting with that premise, here are some basic facts about nursing homes today.

Defining nursing homes

Nursing homes are, in bureaucratic language, *skilled nursing facilities* (abbreviated as SNFs and pronounced *sniffs*). Nursing homes, unlike assisted-living or other community settings, offer skilled care by professionals such as nurses, doctors, and therapists. For instance, nurses administer intravenous (IV) injections and physical therapists help residents regain or maintain function. The facility may have a medical director on-site, or a doctor may be on call.



REMEMBER

Nevertheless, the amount of time these professionals spend with patients is limited. Most nursing-home services are provided by aides (called certified nursing assistants or CNAs) who do personal care and assist with activities of daily living (ADLs), such as bathing and dressing. Federal law requires CNAs to have a minimum of 75 hours of training, although some states require more training. CNAs are the people with whom residents have the most contact. Getting to know them as individuals is important.

Nursing homes vary by type of ownership:

- » Voluntary homes are run by nonprofit organizations, which may be sponsored by religious, fraternal, or community organizations.
- » Public or municipal homes are owned and operated by local governments.

» Proprietary homes are run by for-profit corporations, which may have only a few facilities or be national in scope. This sector now constitutes 69 percent of all nursing homes.

The type of ownership of a nursing home provides no guarantee of quality, which should be assessed individually. There is some evidence to suggest that nonprofit nursing homes offer better-quality care.

Some nursing homes are large, and some are very small. Most nursing homes have between 50 and 200 residents, according to the CMS Nursing Home Data Compendium of 2012. (CMS is the Centers for Medicare & Medicaid Services.) But again, size isn't the key determinant of quality. Small homes may offer a more intimate environment, but large homes may have more specialized staff and more activities.

Moving from a hospital to short-term rehab

More than 60 percent of nursing-home admissions come directly from hospitals, so it's not surprising that most people face the decision about entering a nursing home in a crisis or just after one. The crisis may be a stroke, a bad fall, or a worsening of a chronic condition. Going home from the hospital may be the preferred choice, but the family may not be able to provide the needed care, even with the home healthcare and rehabilitation therapy that Medicare and other insurance coverage provide. A short stay in a skilled nursing facility rehabilitation program is one option that can give the person and family time to adjust to the new requirements and be better prepared to manage at home.



TIP

Don't panic if the hospital nurse or social worker says, "We're sending you to a nursing home tomorrow." Although this information shouldn't come at the last minute, it often does. It usually means you're being referred to a short-term rehabilitation program at a nursing home, not being sent to a nursing home permanently.

In these situations, you'll be asked to make a quick decision about which nursing-home rehab program to choose, and the choices may be limited. The discharge planner at the hospital may hand you a list of three or four nursing homes in the area and say, in effect, "You choose." The discharge planner will then see what

is available right now. Your choices may be limited by the facilities' bed capacity, their ability to provide the kind and level of care needed, location, whether they are part of your health plan's network, and other factors. Frequently the list includes only those nursing homes with which the discharge planner works frequently; it may not include the full range available and appropriate. Some hospitals are creating post-acute networks of SNFs to facilitate transfers.

If you're interested in nursing homes not on the list, you can ask that specific nursing homes be added, but the hospital won't keep your parent until a bed in your preferred nursing home becomes available. You can try to push the hospital to delay discharge for a few days, and you can file a formal appeal to postpone it. (If you lose the appeal, however, you'll have to pay the costs of the additional hospital days.)

The push to move patients quickly from hospitals to nursing homes is in hospitals' and nursing homes' economic interests. Hospitals want to ensure that they can discharge their patients quickly, and nursing homes want to maintain that source of new income.

Medicare Part A pays for the initial episode of SNF services if the person has been discharged after a minimum three-day hospital admission, but patients don't always get to stay for three days. In 2021 Medicare pays for the first 20 days of each benefit period; you pay a coinsurance of \$185.50 per day for days 21–100, and you pay all the costs for each day after day 100. You must be hospitalized for three days to start a new benefit period. During the COVID-19 pandemic, you may be able to get renewed coverage for this service without having to start a new benefit period. And if you're not able to be in your home during the pandemic or are otherwise affected, you can get this level of care without a qualifying hospital stay. If you have a Medicare Advantage plan or private insurance, check with the plan.



WARNING

To be eligible for Medicare coverage for short-term rehabilitation services, you must have been formally admitted as a hospital inpatient for three days. After an observation stay, no matter how long the stay lasted, Medicare will not pay. Check to make sure your family member has actually been admitted to the hospital. You can complain to the hospital if you aren't given accurate

or timely information. If you're on observation (not formally admitted), you should receive a Medicare Outpatient Observations Notice (MOON) that describes how this status affects your bill.

There are steps you can take without the pressure of an imminent hospital discharge or a rapidly deteriorating situation at home. The first step is to look broadly at the options in your area. Then you can be more focused on specific nursing homes and how to evaluate them.



TIP

Sometimes a person admitted for a short-stay rehab program is unable to return home as hoped, and then another decision point is reached: to stay in the same nursing home as a long-stay resident or move to another facility. There may be interim steps to prepare for going home — for example, home modifications or hiring extra help. For advice on how to handle that transition, see the United Hospital Fund's Next Step in Care guide "When Short-Term Rehab Turns into a Long-Term Stay" at www.nextstepincare.org/Caregiver_Home/When_Short_Term_Turns_into_Long_Term/.

Comparing nursing homes for a long stay

Nursing Home Compare is an online Medicare tool that includes information on health inspections and complaints, staffing (hours of care provided by nurses and nursing assistants per resident), and quality measures such as incidence of pressure sores. CMS maintains the database that compares more than 15,000 Medicare- and Medicaid-certified nursing homes that provide skilled services at www.medicare.gov/nursinghomecompare. You can search for a nursing home by name or look for nursing homes in your zip code. Medicare also has an extensive guide at www.medicare.gov/Pubs/pdf/02174-Nursing-Home-Other-Long-Term-Services.pdf.

Nursing Home Compare ranks nursing homes based on three ratings, two of which are self-reports by the nursing homes. Only state inspections are external evaluations. These three ratings (from a low of 1 star to a high of 5 stars) are combined to calculate an overall rating. In addition, Nursing Home Compare reports penalties that have been imposed on the facility.



REMEMBER

Nursing Home Compare is a valuable tool that allows you to eliminate some of the lowest-ranking nursing homes. However, it doesn't include many important factors such as the interactions between management and staff and between staff and residents, how residents' individual needs and preferences are addressed, and the general atmosphere and style of the facility. You need to assess these factors in your visits. Given two nursing homes with similar ratings, you need to take the next step of determining which one seems to best meet your needs or those of your parent. (See the following section for help choosing a nursing home.)



WARNING

Keep in mind that Nursing Home Compare includes data from a limited period. More important, even the data coming from inspections in some states may tend to underreport deficiencies. And Medicare uses a grading curve, so exactly 10 percent of nursing homes in any one state are awarded the top ranking of five stars. This means that a lower-ranking nursing home may have just missed the cutoff on the ranking curve; on the other hand, it may mean that the curve limits the number of nursing homes that would fall into the lower categories.

In addition to Nursing Home Compare, many state departments of health have similar comparisons on their websites. Other sponsored websites offer to compare nursing homes, but they generally base their data on government websites and may include only facilities that pay to be on the list. You can also check consumer ratings on websites. These personal stories can give you insights into services and staff, but they can overstate both good and bad experiences in the facility.

Visiting Nursing Homes

A nursing-home visit is essential if you're deciding which facility is the best fit. Doctor and family recommendations are important, but nothing compares to what your own senses can tell you during a live visit.

The federal Centers for Medicare & Medicaid Services (CMS) sets minimum standards for nursing homes. States, however, are responsible for monitoring and ensuring that nursing homes provide the required level of care. Some states go beyond the federal requirement, but others aren't so diligent.



Make sure you discuss the choices with your parent if possible. This may be difficult, but you can make a much better decision if you get as much information as you can about what's important to your parent: location, language spoken in the nursing home, meals, visits, activities, and so on. If your parent is unable to participate because of cognitive impairments or a medical condition, think of what you know she values as you visit facilities.

Checking off important points

After you've narrowed the possibilities through Nursing Home Compare, your state's Department of Health, or another source (as I explain earlier in this chapter), you can begin to focus on the most likely facilities. Medicare has a seven-page "Nursing Home Checklist" at www.medicare.gov/NursingHomeCompare/checklist.pdf. It is meant to be filled out at each nursing-home visit and has room for your comments.

You can fill in basic information, such as whether the nursing home is Medicare- and Medicaid-certified and whether it has the level of care you need, including specialized services such as ventilator care or a special unit for persons with dementia.



Just because a nursing home has a dementia or "memory care" unit is not a guarantee that it provides good-quality dementia care. Many residents with dementia may not even be on the special unit, and the staff may not have special training or expertise in providing person-centered care for people with dementia. If this is a priority, you need to investigate further.

A particularly important factor noted on the checklist is location. You want to be close enough so family and friends can visit often. Their continued involvement at the nursing home is critical to residents' happiness and well-being. Getting to know the staff, participating in activities, observing different situations — all these interactions are not just nice things to do but also indications to the staff that someone cares deeply about residents and will be actively engaged in monitoring their care. Don't underestimate the importance this may have in the quality of care.



Don't rush through your nursing-home visit, and make sure to visit more than once, preferably at different times and on different days of the week. Evening and weekend visits are especially important because staffing is likely to be lowest at these

times. If you're using a checklist, using your eyes, ears, and nose is more important than completing every item. You can find out a lot just by observing how people talk to each other, whether there are smiles and touching, or whether the atmosphere is chilly and controlled. Often the person who takes you on a tour of the facility is a salesperson who will not be part of your daily experience after admittance.

Here are some categories to review during a nursing-home visit, with a few specific examples:

» Resident appearance:

- Are the residents clean and well groomed?
- Are they appropriately dressed for the time of day and season?

» Living spaces:

- Is the nursing home clean, well lit, and free of offensive odors? Note the use of sprays that cover up odors.
- Is the temperature comfortable?
- Is smoking allowed? If so, is it restricted to certain areas?
- Are all common areas, resident rooms, and doorways designed for wheelchair use?

» Staff:

- Does the staff appear to be polite and respectful to the residents?
- Does the staff wear name tags?
- Does the management run background checks for abuse and neglect before hiring staff? Are these state or national checks?
- Is there a licensed nurse on duty 24 hours a day and a registered nurse present at least 8 hours a day?
- How are physician services provided? Is there a full-time medical director on-site?
- Do families hire private duty nurses or aides to supplement care?

» Residents' rooms:

- Can residents have personal belongings and furniture in their rooms?

- Is there adequate storage space?
- What policies and procedures are in place to protect personal belongings and recover or compensate for their loss?
- Do residents have access to a personal phone, TV, and computer? Is there access to cable TV and the Internet? What are the costs?

» Menus and food:

- Do residents get a choice of food at each meal?
- Can the nursing home provide for special dietary needs (low-fat, kosher, halal)?
- Are nutritious snacks available? How are they offered? Do residents have to request them?
- How many staff are in the dining room during mealtimes to assist residents?

» Activities:

- Ask to see a monthly activity calendar for three consecutive months, not including December (when holiday parties dominate).
- How are residents who are unable to leave their room able to take part in activities?
- How do staff encourage and facilitate residents' use of outdoor areas?
- Are trips to places outside the facility scheduled? What kind, how is transportation provided, and is there an additional cost?
- How are residents' views on the choice of activities solicited?
- If your family member enjoys certain activities like reading, knitting, or attending religious services, how does staff make these available?
- How does the facility provide opportunities to explore creative activities such as art, music, or writing?

» Care:

- Does the nursing home ask about someone's personal routines as soon as he is admitted? For example, someone should note what time the resident gets up in the

morning, what time he goes to bed, and when he prefers to take a shower or bath. In a person-centered approach, residents have more choices about their schedule, and quality of life is the focus.

- Is the same staff assigned to take care of the resident most days? Consistent assignment helps develop good relationships.
- Is there transportation for doctor appointments or other reasons? Will an aide accompany the person if you or another family member can't?
- Are there regularly scheduled care planning meetings with staff to discuss what is going well, what needs to be changed, and who will be responsible for carrying out the suggestions? If you can't attend at the scheduled time, can the meeting be rescheduled or can you participate by conference call?

» **Safety:**

- Are exits clearly marked?
- Are there smoke detectors and sprinklers?
- Are handrails and grab bars appropriately placed?
- Do you understand the details of the required emergency evacuation plan? Make sure you get a copy. What are the plans for notifying you in case of an evacuation?

» **Resident or family council:** The 1987 Nursing Home Reform Law gives residents and family members the right to form independent councils to discuss issues related to care, safety, activities, or whatever else is appropriate.

- What is the name of the head of the family council, and how can you contact him or her? The person leading the family council should not be a nursing home employee. Staff may attend resident or family council meetings only at the request of the council.
- How does the nursing home inform family members of council meetings? Do notices appear in newsletters, bulletin boards, or monthly billing?
- How often does the council meet?
- What issues have been raised by the council?
- How have these issues been addressed?

Noting policy details

Medicare's nursing-home checklist and other similar checklists give you basic information about the nursing home, but they may not tell you everything you want to know. Here are some important questions to ask:



WARNING



TIP

» **What is the nursing-home policy about transfer to an emergency department (ED)?**

Is a family member consulted? In the past six months, how many residents were transferred to the ED and then returned to the nursing home for “care in place” — that is, providing the needed medical care at the nursing home?

Sometimes family members request transfer to an ED when they suspect something is wrong. And sometimes they're right because they notice small changes or big problems that staff may have ignored. However, transfer to an ED is not necessarily a good move. In general, you want to avoid these transfers, which can be unnecessary and result in confusion, frustration, and even deterioration in the resident's condition.

Ongoing communication with staff will help you determine when a real emergency occurs, what can be handled at the nursing home, and when a physician needs to be called. But trust your own instinct as well. You may be seeing something new that staff have ignored. Improvements in this area have been demonstrated with the INTERACT training and interventions for reducing transfers to hospital EDs from nursing homes. More information is available at www.pathway-interact.com. Although intended for staff training, these tools can help family members recognize and report problems so that these transfers can be avoided.

» **Does your family member have an advance directive that outlines the types of care she wants or does not want?**

Does it include preferences about CPR (cardiopulmonary resuscitation)? Is this information known to all staff and easily available for ambulance and ED personnel?

» **What is the nursing home's policy or practice about feeding tubes?**

Sometimes feeding tubes are recommended (with accompanying risks) because feeding by hand takes too long, not because it is medically necessary. This is a complex decision that should be discussed thoroughly and not seen as routine practice.

» **What kind of training do staff receive for specific situations?** Are they trained in dementia care? Do they receive sensitivity training about working with lesbian or gay residents or residents from different cultural or religious backgrounds?

Getting answers to these questions helps in streamlining your options and making the best choice possible.

Responding to Residents' Problems in Nursing Homes

Selecting the best nursing home is critical, but your responsibilities do not end there. Because this will be a long stay, it is important to monitor the quality of care and deal with problems that may arise. You and your family member have a right to expect good-quality care, respect, and sensitivity to any special issues.

Still, the situation that exists when your family member is admitted may change over time. Your family member's condition may deteriorate, her roommate may become agitated, and her favorite aide may leave and be replaced by a competent but not-so-friendly person. You should be familiar with residents' rights in nursing homes and be a vocal advocate for ensuring that they are enforced. At the same time, you should distinguish between situations that are unacceptable and those that can be the focus of compromise and negotiation. Of course, if the problems involve serious incidents of abuse or neglect, you should take immediate action.

If the problem does not involve abuse or neglect, is isolated, and can be resolved, your first approach should be a frank but friendly discussion with the staff person who is the source of the problem. For example, your parent doesn't like the shampoo the aide is using because it stings if it gets in his eyes. Maybe a different shampoo or technique will solve the problem.

If the problem is more serious or you see it happening to other residents, but it hasn't risen to the level of abuse or neglect, then speak to the head nurse or the director of the nursing home. Most nursing homes want satisfied residents and family members

and will generally try to resolve the problem. Of course, you may encounter some defensiveness or denial.



REMEMBER

If these informal approaches fail, then your next recourse is to contact your state's *ombudsman*, a person assigned to investigate complaints in nursing homes, adult homes, and assisted-living facilities. The Long-Term Care Ombudsman Program is run by the U.S. Administration on Aging and has volunteers and staff in every state (see ltcombudsman.org/about/about-ombudsman for information, including a state map). To find your local ombudsman office, call ElderCare Locator (800-677-1116) or your State Health Department. In some areas you can call Adult Protective Services. Police should be called if the resident is in imminent danger. Be prepared to document your concerns with dates, names, and specific violations. Try to take pictures of visible violations to further support your claims.

Get familiar with the comprehensive list of nursing-home residents' rights, which every nursing home is required by law to observe. If you can link the problem to a violation of patient's rights, you'll be on stronger ground.

If the problem persists, you can file a formal complaint with your State Health Department. There are other avenues such as private litigation that you may want to investigate.

IN THIS CHAPTER

- » Talking with your family about advanced illness and trauma
- » Creating the paperwork to make your wishes known
- » Understanding palliative care and hospice

Chapter **11**

Getting the Healthcare You Want (and Avoiding What You Don't Want)

Of all the difficult topics to discuss in planning for the future, the one most avoided is what you want to happen should you become seriously ill or have an accident. But all too often, the discussion of what to do if you become incapacitated and can't speak for yourself happens only in a crisis — the worst time for thoughtful and well-informed conversations.

Nothing will make these profound discussions easy. But you can lay the groundwork in ways that increase your family's chances of being prepared when decisions about treatment and level of care must be made. This chapter suggests ways to organize your thinking, create legal documents, and understand care options. This chapter covers the types of documents you can create in advance of an emergency, how to choose a *healthcare proxy* (someone to speak on your behalf if you're incapacitated), and the difference between palliative care and hospice. Both are potential choices in serious illness but have different goals and insurance coverage.

Talking about Future Healthcare Decisions

It's hard to think about it, but there may come a time when you may be ill and not able to speak for yourself. Anyone at any age can be in an accident or develop a serious illness. But as people age, the likelihood of an event requiring a treatment decision increases. And a quick conversation about a friend's situation or a news report most likely will not ensure that your own wishes are understood and followed. What everyone should do is start a series of conversations with family, doctors, clergy, or other trusted individuals. In this section, I underline the importance of the different aspects of care that you should address in advance. Another good resource is AARP's *The Other Talk: A Guide to Talking with Your Adult Children About the Rest of Your Life* by Tim Prosch (McGraw-Hill).



TIP

The Conversation Project has materials to help families talk about advance care planning. See its website at theconversationproject.org.

Realizing the importance of advance planning

No one can predict how and when the need for someone else to make a medical decision for you will arise, what the medical situation will be, and what choices will have to be made. That is why a series of discussions is more likely to convey your thinking in depth than a one-time conversation.



REMEMBER

Although you and your family members are probably reluctant to have a serious discussion about the possibility of a serious injury or illness, keep in mind that talking about it does not make it happen. In fact, everyone will probably feel better afterward. However, wishes may change, so it is important to review any documents you have created at least every few years and more often if warranted to make sure they still reflect your current thinking. The results of the conversations can then be incorporated in a variety of documents, which I describe in the following sections.



If you don't have a documented advance care plan, state law will determine who makes decisions for you. Most states have a priority list of family members who will be chosen to speak for you when you can't make a healthcare decision. The person you would have chosen to speak for you may be far down on the list or not on it at all. And if family members can't agree, a court may be called upon to make the decision.

Making wishes known with advance directives and living wills

An *advance directive* or *living will* is a general term for a document that tells healthcare providers the kinds of medical treatment you do or do not want. For example, you may want to refuse tube feeding or ventilators or antibiotics if, in your view, they will not provide you with sufficient benefit, even if they may prolong your life. You have a right, which is well established in law and medical ethics, to refuse any treatment for whatever reason. You can also say that you want all treatments that offer any possibility of prolonging your life, even if they will be painful or burdensome.

But you do not have a right to demand any particular treatment because healthcare providers may not be willing to provide it for reasons of conscience or because they consider it *futile*, a vague term but one that carries some weight in medical and legal circles. If they refuse to treat you according to your documented wishes, they must refer you to another provider or go to court to challenge your wishes or your capacity to make this decision.

With advance directives, you can also name the person you want to make healthcare decisions on your behalf if you're unable to speak for yourself. The choice of your healthcare proxy (sometimes called a healthcare agent or surrogate decision maker) is especially critical because the decision may not be clear-cut and may require interpretation of what you have expressed in the advance directive (information on choosing a healthcare proxy appears later in this chapter). Did you mean, for example, no antibiotics ever or just when they would prolong dying? Would you have agreed to a trial of a therapy to see whether it improved your condition? Talking about these questions ahead of time gives your healthcare proxy some guidance.



REMEMBER

An advance directive comes into play only when the person is unable to make healthcare decisions. If, for example, you and your parent disagree about whether surgery is advisable, and you are the healthcare proxy, you can't decide in favor of surgery without your parent's consent. Usually the healthcare proxy takes over when the patient is in a coma or unconscious, or a doctor determines that the patient is unable to make healthcare decisions.

Dealing with the Rules of Advance Directives

As with everything in medical care, paperwork is involved in making your wishes known. When you plan ahead and make your wishes clear, all parties involved will have a road map to follow and transitions will be smoother. Take a look at the following sections to put advance directives into motion.

Finding the forms for advance directives and living wills

To start putting together your advance directives, your first (but not only) option is a state-approved advance directive form that tells your doctors, either in general terms or in detail, your wishes regarding treatments. The form often includes a section where you can express your wishes on organ donation. For a state-by-state map of advance directives requirements, see www.everplans.com/advance-directive. If you spend a lot of time in more than one state, it's a good idea to complete each state's advance directive.



TIP

You don't need a lawyer to create an advance directive or a living will, but you do need to follow your state's requirements about signing and witnessing these documents. Many online kits provide a template for an advance directive. If you use one of these, make sure you complete it following your state's rules. If you're unsure of whether you have met your state's requirements, consult a lawyer or other trusted professional.

Putting your wishes down on paper

A popular form of advance directive is the *Five Wishes* document. This document, written with the help of the American Bar Association's Commission on Law and Aging, gives you the opportunity to convey your personal, emotional, and spiritual needs as well as your medical wishes. In 42 states and the District of Columbia, it substantially meets the legal requirements for an advance directive. Check <https://fivewishes.org/Home> to see whether your state is included. Even if it isn't, you can complete the Five Wishes to accompany your state's approved advance directive.

Here are the five categories of wishes:

- » The person I want to make care decisions for me when I can't
- » The kind of medical treatment I want or don't want
- » How comfortable I want to be
- » How I want people to treat me
- » What I want my loved ones to know

Each of the sections contains an extensive list of things to consider. For example, the document describes four situations — close to death, in a coma and not expected to wake up and recover, permanent and severe brain damage and not expected to recover, and in another condition in which I do not want to be kept alive — and lists the choices that may apply. You can access and fill out the Five Wishes form online at <https://fivewishes.org/five-wishes>.

Choosing a healthcare proxy



REMEMBER

One of the most important decisions you can make is the choice of *healthcare proxy*, surrogate, or agent: the person who will make healthcare decisions for you when you're unable to do so yourself. This person should be someone you trust to put your wishes ahead of his own feelings. A calm, careful approach to problem solving is an asset, as is the ability to listen to other points of view and mediate differences of opinion. The ability to absorb medical information and ask clarifying questions is a valuable skill. Disagreements often stem from poor communication about the person's medical condition, and sometimes doctors are reluctant to give bad news in a direct and nonevasive way. The proxy may have to read between the lines or ask very direct questions.

Location is another factor in choosing the person; although your healthcare proxy doesn't need to live with you or even in the same town, it's not a good idea to pick someone far away in case decisions must be made quickly.

A family member is usually the first option, but you may want to choose a friend instead. (Your doctor can't be your healthcare proxy.) If you have siblings or more than one child, think which one best meets these personal characteristics, regardless of birth order, age, or profession. It's a good idea to choose an alternate as a backup.



TIP

Make sure your healthcare proxy understands your wishes. Many people chosen as healthcare proxies may ask a doctor, "What would you do if this were your mother?" This isn't a good question because it assumes that their mother and the doctor's mother have the same history, beliefs, and wishes. The doctor's mother may have wanted something very different from what their mother expressed. Many experienced doctors deflect this question by saying, "Tell me a little more about your mother." That conversation can lead to a better understanding of the options.



REMEMBER

Before naming your healthcare proxy, be sure to discuss this responsibility with the person you think is best suited for the job and ask whether he is willing to take on this responsibility. It should never be a surprise to that person. Make sure you tell other involved family members about whom you have selected to make medical decisions for you. They should not be surprised either. If you're the healthcare proxy, make sure you keep other family members informed about what is happening and what is likely to happen. Many deathbed family conflicts arise because of lack of communication, which leads to lack of trust.

Adding do not resuscitate (DNR) orders

Do not resuscitate orders are a special kind of advance directive. They tell doctors, nurses, emergency medical technicians, and others that a person has decided not to undergo CPR (cardiopulmonary resuscitation) if his heart stops beating or he stops breathing. A doctor must sign the DNR order for it to be active. In a hospital or other healthcare facility, staff will start CPR if there is no DNR in the medical record.

Why would anyone not want CPR if it can restore a heartbeat? Success rates for CPR vary, but much depends on the person's overall medical condition. CPR may not be effective for older people with serious chronic conditions. And these interventions can be quite brutal, leading to broken ribs and other injuries, especially for an older person.

Most state laws authorize a doctor to enter a special DNR order that will be honored outside the hospital. This is important because when emergency medical technicians respond to a 911 call at home, they are legally required to start CPR unless there is an out-of-hospital DNR order signed by a doctor.



TIP

Even with the proper documentation, in the heat of the moment, sometimes DNR orders are ignored. Or, as the ambulance pulls up, the paperwork can't be found. At home the DNR order should be easy to find, not something that has to be hunted down in a crisis. You can post the DNR order on the refrigerator door, for example, or on an easy-to-see bulletin board.

Because a DNR order is a doctor's order, you'll need to ask your doctor to fill out the form. If she is reluctant to do so, ask why. It may be a good way to start an important conversation about your wishes.

Keeping your advance directive accessible

A carefully completed advance directive is useless if no one knows where it is when you are seriously ill or in an accident. A safe deposit box is great for precious jewelry — but not for advance directives.

Discuss your advance directive with your doctors, and tell them the name and contact information for the person you have selected as a healthcare proxy. You should provide a copy of the document, which can then go into your medical record. In a hospital, a doctor called a *hospitalist* (a specialist in critical care medicine) will probably oversee your care, so it is essential to have the advance directive as part of your hospital record. When you're admitted to a hospital or other healthcare facility, you'll be asked (it's a federal requirement) whether you have an advance directive. If this is a planned admission, be sure to bring the document with you.

Your healthcare proxy should have a copy of your advance directive as well as any supporting material that documents your wishes. You should review the advance directive every few years, or more often if your health condition changes. The document should have a relatively recent date. A document created 15 years ago is likely to make someone ask, “But what if he changed his mind?”



TIP

You can register your advance directive online at www.uslivingwillregistry.com. It will then be available to all providers. Be sure to update the registry if you change the document. Another resource is the American Bar Association’s toolkit on advance directives. See www.americanbar.org/groups/law_aging/resources/health_care_decision_making/consumer_s_toolkit_for_health_care_advance_planning.html.

Choosing Physician Orders for Life-Sustaining Treatment (POLST)

A recent development in advance directives is the Physician Order for Life-Sustaining Treatment (POLST). POLST started in Oregon but has spread to many states. In New York, it is called MOLST (Medical Orders for Life-Sustaining Treatment), and in Iowa, IPOST (Iowa Physician Orders for Scope of Treatment). Programs in other states have their own names. See polst.org/programs-in-your-state/ for a state-by-state listing of POLST Paradigm programs.

The names and forms may vary by state, but the basic idea is the same. The POLST is intended for people with serious advanced illness who may be expected to face major treatment decisions within a foreseeable time. The form lists medical interventions you can choose, ranging from comfort care to full treatment, and there is a place for additional orders. The patient (if able), the legally recognized decision maker (if there is one), and a physician must sign the form.

The POLST form is intended to be sent with the person upon transfer. For instance, an EMT can follow a POLST directive if 911 is called. If a person is transferred from hospital to nursing home, the POLST form describes to the nursing-home staff the treatment plan that should be in place.

Why would you need a POLST if you have an advance directive, a living will, and Five Wishes, as well as a healthcare proxy? Because these can be insufficient to guarantee that your wishes will be followed. Hospital, nursing-home, and other clinical staff may be wary of following anything but a physician's order, even though your paperwork is signed and legal. A medical order signed by a physician helps ensure your wishes are followed.

But a POLST isn't intended to take the place of more traditional advance directives. Although the POLST program addresses a common problem of medical staff failing to follow a person's wishes even when documented in an advance directive, it doesn't take into account the fuller range of choices recognized in, for example, a living will or Five Wishes.



REMEMBER

In the most common situations in which POLST is used, the discussion preceding the physician's signing of the order is brief and limited to the items on the checklist. And hospital staff may not have training or experience in discussing the options with the patient, healthcare proxy, and family. POLST addresses a serious shortcoming in medical practice, but be sure to have more traditional advance directives in place as well.

Understanding Care Options for Serious Illness: Palliative Care and Hospice

"There is nothing more we can do" is one of those phrases that should be erased from the medical vocabulary. Perhaps there is nothing to be done to cure a patient. But something can always be done to keep a person's pain and symptoms under control and to support the emotional and spiritual needs of a person with advanced illness and the family that experiences distress and loss.

Two options that stress holistic management of serious, life-threatening illness are palliative care and hospice. They are different but related. Both suffer from misperceptions that choosing either means "giving up," as if serious illness were something that can be cured by willpower or yet another last-ditch effort. Some people do not want to die in full battle mode but are urged on by doctors and family to try one more round of chemotherapy

or a drug that is still being tested and has nasty side effects. Hospice and palliative care provide other, more peaceful options.



REMEMBER

Both palliative care and hospice are voluntary choices. No one can force you to accept this type of care if you don't want it.

Palliative care

Palliative care is a relatively new medical subspecialty practiced by specially trained physicians, nurses, physician assistants, social workers, clergy, and others. Most palliative care is delivered by hospital teams, but home-based services are increasingly available. Palliative care offers services that improve how individuals function in everyday life, even as they undergo active treatment for a serious illness. Care focuses on pain relief, symptom control, and improving quality of life. Palliative care can be time-limited or ongoing. The ill person and family members are considered part of the palliative care team.

Palliative care can be provided along with treatments intended to cure. It can be started at any point in an illness. In fact, palliative care specialists urge people to consider palliative care at an early stage because the kinds of treatments offered can make it easier to go through the rigor of a chemotherapy regimen, for example.



REMEMBER

Palliative care is covered by most health plans, including Medicare under Part B, Medicaid, and private insurance, on a fee-for-service basis. However, there is no special Medicare benefit for palliative care as there is for hospice. The Medicare hospice benefit is a package of services covered under Part A and doesn't require copays or deductibles. However, the hospice benefit coverage is based on a doctor's determination that the person has six months' or less life expectancy. If, in a hospital setting, you feel that more needs to be done to control pain or discomfort, ask for a consultation with the palliative care team or specialist. This request does not mean changing doctors; it is asking for special expertise to deal with the problems.

For more information about palliative care, go to the Center to Advance Palliative Care at getpalliativecare.org. The website includes a listing of palliative-care resources that you can search by state and city. For a guide comparing hospice and palliative care, see the United Hospital Fund's Next Step in Care website at nextstepincare.org/Caregiver_Home/Hospice.

Hospice

Hospice is a comprehensive service that focuses on controlling pain and symptoms and improving the quality of life for people with a life-threatening illness who have short life expectancies (six months or less). Hospice is a form of palliative care for people who aren't being helped by active treatment or for whom the burdens of treatment outweigh the benefits. People choose hospice when they want to spend their remaining time without aggressive treatments and with care that focuses on comfort and quality of life. Entering hospice requires forgoing treatment intended to cure.

Hospice is a team approach that uses the skills of different medical and nonmedical specialists to create an environment of comfort and emotional and spiritual support for both the patient and the family.

Hospice services may include, in addition to doctors and nurses, physical and occupational therapists, social workers, volunteers, and clergy. Other services are

- » Medications to relieve nausea, pain, shortness of breath, agitation, and other symptoms
- » Medical supplies such as a hospital bed or a wheelchair
- » Support for the family, including counseling and teaching how to do certain healthcare tasks
- » A short hospital stay if the person's symptoms can't be managed at home
- » Short-term respite care — time off for the family
- » Volunteers to provide companionship
- » Bereavement counseling for the family for a year after the person's death

Sometimes doctors recommend hospice, but in other cases a family member has to begin the discussion. If you ask about hospice and are criticized by a doctor or nurse, ask why they are opposed to the idea. If you aren't satisfied, ask for a second opinion.



Hospice is not right for everyone. Some people want to pursue aggressive treatments to the very end. Home hospice may also require a considerable amount of caregiving by the family. Having new people involved in care may seem overwhelming at a time of great emotional stress. But hospice offers an opportunity for care that sees the whole person and the family as the unit of care and works with them to achieve the best quality of life possible.

Hospice at home or in a facility

In the United States, most hospice services are provided at home, but they can also be provided in nursing homes and assisted-living facilities, which may contract with a local hospice to provide the care. There are, in addition, inpatient hospices in some hospitals and free-standing hospices.

Although a team of professionals, as well as volunteers and aides, provides home hospice services, much of the care is provided by family members. Only in the last few days of life is there likely to be constant care by a member of the hospice team. However, one of the benefits of hospice is that you have a 24-hour number to call if an unexpected problem occurs. A hospice nurse can offer advice and make a home visit if necessary, which can reduce unnecessary and stressful visits to the emergency department.

Hospice benefits under Medicare, Medicaid, and private insurance

Hospice is a benefit under Medicare Part A and is included in Medicare Advantage plans. All other Medicare benefits under Parts A and B continue, including the attending physician's fees. You can continue to get services for conditions that aren't related to the terminal illness. Although it is not one of the mandatory benefits that federal regulations require state Medicaid programs to provide, such as hospital and home healthcare services, most states and the District of Columbia do offer hospice services. The services may vary, so check with your state's Medicaid agency. Most private health insurance plans follow Medicare guidelines on hospice.

To be eligible for the Medicare hospice benefit, a doctor must certify that a person has a six-month or less life expectancy. Some diseases, such as cancer, follow a more or less predictable course.

But others, like Alzheimer's disease, do not, and it is much harder to say how much longer a person with Alzheimer's is likely to live. As a result, hospices have been criticized both for taking patients with only a few days to live, when they can't get the full benefit of the services, and taking patients with an unpredictable disease course, which results in higher costs.

Tips for choosing the right hospice

Choosing a hospice, like choosing a home care agency, an assisted-living facility, or a nursing home, requires some research on your part. Here are some questions to ask:

- » Is the hospice certified by Medicare, which means that it meets federal and state guidelines?
- » Is there someone to call 24 hours a day, seven days a week?
- » How does the hospice manage medical emergencies?
- » What kinds of medical equipment will be provided?
- » Although accepting hospice means giving up treatments intended to cure, many medical interventions such as chemotherapy to relieve symptoms and anti-nausea medications are important adjuncts to hospice care. What is the hospice policy on these kinds of treatments?



TIP

You can find out about hospices in your area by asking the doctor, hospital, or state health department or by going to www.medicare.gov/hospicecompare/. This website gives basic information about hospice services in your area.

You can find a list of state hospice associations at hospicefoundation.org/Hospice-Directory. Make sure you check several sources to get a complete list, as some websites list only hospices with which they are affiliated.

Ending hospice care



REMEMBER

A person in hospice care has the right to discontinue the services at any time for any reason. Perhaps your parent is getting better because of the extra attention (some studies show that people in hospice care live longer than those who don't get this care). You can always cease hospice care for a while and start again when

necessary. Also, the hospice can discharge the patient. This happens rarely, but usually the reason is that the person wants to pursue treatments intended to cure or no longer meets hospice criteria. The hospice may also say that the home is not safe for its workers or that the family refuses to cooperate with hospice rules. Hospice programs can't discharge people because their care is inconvenient or too expensive.

Some hospices have been forced to close because Medicare auditors determined that they were keeping people for extended periods and their claims were denied. So hospices may be wary of taking persons who have unpredictable courses of illness.

- » Turning to federal and state agencies for help
- » Taking advantage of community programs

Chapter **12**

Ten (Plus Six) Resources to Help You Navigate Your Later Years

The options for the future are varied and sometimes complicated. The good news is that a lot of information is available from many different sources. The bad news is that the information is often incomplete or inaccurate, and hard to apply to your personal situation.

With the suggestions in this chapter and some judicious selection, you can find reliable sources of basic information to get started. You can narrow your search to the sources most likely to be helpful. Even then, you should double-check the information to make sure you have accurate facts and figures. All this research can be a lot of work, so you may want to ask a friend or family member to help you with this process.

Checking Out Federal Programs

Federal agencies — primarily the Centers for Medicare & Medicaid Services (CMS), but also other agencies such as the Administration for Community Living, the Administration on Aging,

and the Social Security Administration — are good places to begin when you have questions or are looking for information. (Medicaid is a federal-state program, so it is important to look at both the federal rules and your state's program.) Throughout this book I refer to specific online links, but here I give an overview of some of the main resources.

Medicare and Medicaid

Even though Medicare doesn't cover long-term care, it's an important resource for the medical care that people receiving long-term care services and supports need. Some of the short-term benefits — for example, for home healthcare or rehabilitation services — may fill gaps while more viable long-term solutions are arranged.

CMS, part of the U.S. Department of Health and Human Services, oversees Medicare. Its website, www.medicare.gov, is the primary resource for beneficiaries and families.

Medicaid is the federal-state program that provides healthcare and long-term care for people with low incomes and assets or very high medical costs. Eligibility and services vary by state. Much of the information on the Medicaid website, www.medicaid.gov, is designed for regulators and policymakers, although it includes links to state sites, which have more specific information for residents. This is just a place to start; you'll need to dig into the information on the state Medicaid website and other sources.



TIP

See Chapter 7 of this book or check out AARP's *Medicare For Dummies* by Patricia Barry (Wiley) for more detailed information on Medicare and Medicaid. These sources cover the basics, including the differences between Original Medicare and a Medicare Advantage plan. If you need help choosing a Medicare Advantage plan, you need to do further research on local plans.



TIP

You may also find the following CMS websites useful:

- » **Comparing hospitals:** www.medicare.gov/hospitalcompare/search.html
- » **Comparing physicians:** www.medicare.gov/physiciancompare/
- » **Comparing dialysis facilities:** www.medicare.gov/DialysisFacilityCompare/search.html

You can see a directory of equipment suppliers that participate in Medicare's competitive bidding program at www.medicare.gov/SupplierDirectory/.



WARNING

These or other comparison sites are useful as a starting point, but they don't provide all the information you need, and the sources on which they base their reviews may be incomplete or outdated.

Other federal agencies

Aside from Medicare and Medicaid, the following federal agencies can provide information you may find useful in your research:

- » **Administration for Community Living:** In 2012, the U.S. Department of Health and Human Services created an umbrella organization, the Administration for Community Living (ACL), to bring together various federal agency resources to coordinate policy and reduce fragmentation in policies on disability and aging. The main website is www.acl.gov, and the ACL has many resources on long-term care at <https://longtermcare.acl.gov/>.
- » **Administration on Aging:** The Administration on Aging (AoA) is part of the ACL. AoA supports what is often called the *Aging Network* of agencies and professionals. It provides support services, nutrition services, preventive health services, the National Family Caregiver Support Program, elder-rights services, and services to Native Alaskans, Native Hawaiians, and Native Americans. Its website is www.acl.gov/about-acl/administration-aging.
- » **Eldercare Locator:** The Eldercare Locator, a free service of the AoA, is a basic go-to site for locating resources in your community. Its website is <https://eldercare.acl.gov/Public/Index.aspx>.
- » **Area Agencies on Aging:** The more than 600 Area Agencies on Aging (AAAs) provide information and referrals to services such as adult daycare and senior-center programs in their region. To view a map of AAAs, enter your city and state or zip code at www.n4a.org/about-n4a/?fa=aaa-title-VI, or click on the Eldercare Locator link near the bottom of the page for more information. Some state associations of AAAs also have maps of their locations within the state.



TIP

» **Social Security Administration:** The Social Security Administration (SSA) administers Social Security benefits, which may be an important part of the financial side of your plan. The agency's website at www.ssa.gov lets you check or estimate your retirement benefits online and get other information.

AARP's *Social Security For Dummies* by Jonathan Peterson (Wiley) provides more detail on all aspects of Social Security.

» **USA.gov:** This site is the main federal government portal at <https://USA.gov>. It has a section on senior citizens' resources, which has links to a variety of federal agencies and a separate listing of many state resources.

» **Beneficiary and Family-Centered Care Quality Improvement Organizations (BFCC QIOs):** As part of the CMS structure, each state has a designated BFCC QIO that is responsible for ensuring and improving quality of care and for reviewing complaints. If, for example, you feel that you're being discharged from a hospital too quickly, you can appeal the decision to the local BFCC QIO.



TIP

There are two BFCC QIO organizations — Livanta and Kepro — that cover different regions. Most people don't know about these organizations, but they can be helpful in resolving problems. This website will tell you which organization covers your state: www.qualitynet.org. You can also look up Livanta (www.livanta.com/bfccqio.html) and Kepro (www.keproqio.com) to see the review process.

Getting Information through State and Local Programs

Different states assign aspects of long-term care to different agencies. Finding the right state agency for the information you need can be challenging. For example, Medicare is Medicare wherever you are and Social Security is one system, but Medicaid in Florida is the Florida Agency for Health Care Administration whereas in Wisconsin it is ForwardHealth. More important than the name is the variation in Medicaid from state to state.

After you have located the right agency, make sure to keep a record of how to find it again. Check out the following list for state agencies that are relevant for future care planning:

- » **Departments of aging:** Every state has an agency devoted to services for older adults, often linked to services for people with disabilities. Like Medicaid, however, what the agency is named varies, although not as much. The most common name is Department (Office, Division, Commission) of (for, on) Aging. The National Association of States United for Aging and Disabilities has a state-by-state listing of offices at www.nasuad.org/about-nasuad/about-state-agencies/list-members. These agencies have information about senior centers, food programs, counseling, and other services, both state-funded and in partnership with federal agencies.
- » **County and city departments of aging:** Many counties and cities also have Departments of Aging that contract with local community agencies to provide services. It may be easier to get information from a local agency than from the state, although that may depend on the level of staffing. These are the same agencies described in the preceding section as Area Agencies on Aging.
- » **Advance directives:** The federal Patient Self-Determination Act, enacted in 1990, requires hospitals and other providers and health plans to maintain written policies and procedures with respect to advance directives — documents that spell out what kinds of treatments you do or do not want if you are not able to speak for yourself.



TIP

Caring Connections, an arm of the National Hospice and Palliative Care Organization, has state-specific forms you can download at www.aarp.org/advancedirectives.

Turning to Community-Based Organizations

Public programs are important sources of information, but you may find that information from nongovernmental sources answers more of your immediate questions.



TIP

There is no comprehensive list of these organizations, and there are hundreds of them, so you'll have to do some detective work (a friend or family member can help).

Here are a few sites to get started:

- » **AARP** (www.aarp.org): From the home page you can go to several different subject categories, such as health, work and jobs, retirement, home and family (which includes caregiving), and money (click the "Menu" icon at the upper-left corner of the page). Each of these sections provides information and directs you to other resources.
- » **Alzheimer's Association** (www.alz.org): This site has links to local chapters, which offer educational sessions, support groups, and other services. The main site has information about Alzheimer's disease and other dementias, including research and treatment.
- » **National Council on Aging** (www.ncoa.org): Through its BenefitsCheckUp tool, NCOA has information for older adults on accessing benefits such as help paying for medications or food. The tool is organized by state or zip code.
- » **National Hospice and Palliative Care Organization** (www.nhpco.org): This organization has information about end-of-life concerns and links to help you find providers of both types of services.



TIP

Small organizations may not have staff to respond immediately to your requests. You may have to call back a few times to get the information you need. Be patient but persistent.

Index

A

- AAA (Area Agency on Aging), 34, 153
- AARP, 59, 64, 65, 156
- ACA (Affordable Care Act), 80
- accessibility modifications, 30–33
- activities, at nursing homes, 131
- Acute Care for Elders (ACE) units, 115–116
- ADA (Americans with Disabilities Act), 9
- adaptability modifications, 30–31
- adaptations, to vehicles, 69–70
- Administration for Community Living (ACL), 153
- Administration on Aging (AoA), 153
- ADRCs (Aging and Disability Resource Centers), 93
- advance directives
 - choosing healthcare proxy, 141–142
 - do not resuscitate orders, 142–143
 - Five Wishes document, 141
 - forms for, finding, 140
 - importance of, 7
 - keeping accessible, 143–144
 - nursing home policy on, 133
 - overview, 139–140
 - POLST forms, 144–145
 - registering, 144
 - state resources for, 155
 - updating, 144
- advisers, professional, 13–14
- affinity communities, 60
- Affordable Care Act (ACA), 80
- aging. *See* later years, navigating;
specific related topics
- Aging and Disability Resource Centers (ADRCs), 93
- aging in place
 - community, role of, 25–26
 - hazards in home, 26–29
 - modifications, 29–35
 - obtaining outside help, 35–38
 - overview, 25
- Alzheimer's Association, 156
- Alzheimer's disease, 51, 109
- Americans with Disabilities Act (ADA), 9
- AoA (Administration on Aging), 153
- Area Agency on Aging (AAA), 34, 153
- Argentum, 53
- assets, 90, 101–102, 104–105
- assisted living
 - chronic health conditions, 18
 - continuing care, 59
 - contract types, 54–55
 - creating plan based on profile, 23
 - defined, 48
 - evaluating cost of, 53–57
 - getting information about, 52–53
 - healthcare services offered, 51
 - main components of, 49–51
 - Medicaid waivers for, 92–93
 - other terms for, 48
 - overview, 47
 - state regulations for, 49
 - transportation options, 75
 - visiting, importance of, 57–59
- assistive technology, 37–38
- attorneys, getting advice from, 13–14

B

bank accounts, joint, 96–98
Beers Criteria, 120–121
Beneficiary and Family-Centered
Care Quality Improvement
Organizations (BFCC QIOs), 154
burial, planning, 101
burn prevention, 29

C

car, making adjustments to, 67–70
car services, 75
cardiopulmonary resuscitation (CPR),
142–143
CARE Act, 119
CarFit, 67
CCRC (continuing-care retirement
community), 54–55, 59, 60. *See also* assisted living
Centers for Medicare & Medicaid
Services (CMS), 152. *See also*
Medicaid; Medicare
certified nursing assistants (CNAs), 124
charity prescription drug programs, 86
chores, finding help for, 37
chronic health conditions, 16, 18, 51,
108–111
city departments of aging, 155
climate, when planning location, 11
cohousing arrangements, 61
Commission on Accreditation of
Rehabilitation Facilities, 52
community, importance of, 11,
25–26
community property, 102
community-based organizations,
155–156
community-based services, 8–9, 23,
92–93

continuing-care retirement
community (CCRC), 54–55, 59, 60.
See also assisted living
convenience account, 97
conventional financial power of
attorney, 98–99
cost of living, 12
costs. *See* fees
county departments of aging, 155
coverage gap, Medicare Part D, 85
CPR (cardiopulmonary resuscitation),
142–143
cremation, planning, 101

D

dementia, 51, 129
departments of aging, 155
DME (durable medical equipment),
86–87
do not resuscitate (DNR) orders,
142–143
doctors
as assisted living resource, 52
in charge of medical care, 107
discussing advance directive, 143
do not resuscitate orders, 142–143
geriatricians, 111–113
gerontologists, 111
getting advice from, 13–14
hospitalists, 116, 143
knowing when to change, 112
planning for chronic health
conditions, 18
planning for surgery, 117–119
POLST forms, 144–145
role in decisions on driving, 71
donating household items, 43–45
doughnut hole, Medicare Part D, 85

downsizing

- donating or selling items, 43–45
- emotional aspects of, 12–13, 40–41
- important papers, 42
- moving, 45
- overview, 39–40, 41–42
- sorting and decision making, 42–43
- timing and flexibility, 12–13
- when making renovations, 41

driver, hiring, 75

driver safety courses, 65

driving

- evaluations of, 66–67
- finding alternatives to, 71–76
- giving up, 70–71
- judging whether still safe, 64–67
- making your car fit you, 67–70

drugs, prescription, 82, 84–86, 110, 119–122

durable financial power of attorney, 99–100

durable medical equipment (DME), 86–87

E

Eldercare Locator, 34–35, 52, 153

emergencies, medical. *See* advance directives; healthcare

emergency departments (EDs), 114, 115, 133

emergency systems for cars, 67

entry fee, assisted living, 53–54, 55, 56

estate planning, 106. *See also* probate; wills

estate recovery rules, Medicaid, 91

exchanges (Health Insurance Marketplace), 90–91

executing will, 103

executor, choosing, 103

Extra Help program, Medicare, 85

F

fall prevention, 27–28

family

- advance planning with, 138–139
- allocating tasks to, 35–36
- asking to remove items from home, 42
- as assisted living resource, 52
- CARE Act, 119
- choice of healthcare proxy, 141–142
- considering when planning location, 11
- getting transportation from, 74
- joint bank accounts, 96–98
- in personal profile, 18–19
- planning for later years with, 7
- responding to problems in nursing home, 134–135
- talking about giving up driving with, 70–71
- talking about safe driving with, 66–67

family council, nursing homes, 132

fare assistance programs, 74

federal program resources, 151–154

feeding tubes, 133

fees

- assisted living, 53–57
- Medicare, 80, 81, 82–83

fiduciary duty, 98, 100

financial advisers, 13–14, 22

financial assistance, 34–35, 85–86

financial planning

- attitudes about money, 21–22
- money management, 96–100
- overview, 95
- probate, 104–106
- starting to think about, 6
- wills, 100–104

- financial powers of attorney, 98–100
- fire prevention, 29
- Five Wishes document, 141, 145
- fixed assets, 102
- friends
 - allocating tasks to, 35–36
 - as assisted living resource, 52
 - choice of healthcare proxy, 141–142
 - getting transportation from, 74
 - in personal profile, 18–19
- funerals, planning, 101

G

- garage sales, 44–45
- geriatricians, 111–113
- gerontologists, 111
- gifting household items, 43
- GoGoGrandparent, 75
- group homes, 62

H

- hazards in home, dealing with, 26–29
- Health Insurance Marketplace (exchanges), 90–91
- healthcare. *See also* advance directives; Medicaid; Medicare
 - advance planning, 138–139
 - in assisted living, 51
 - geriatricians, 111–113
 - hospital care, 113–119
 - needs, in personal profile, 16–18
 - overview, 107–108, 137
 - palliative care and hospice, 145–150
 - polypharmacy, 119–122
 - special medical needs, 108–111

- starting to think about, 6
- talking about future decisions, 138–140
- healthcare proxy
 - choosing, 141–142
 - defined, 137
 - giving guidance to about preferences, 139
 - overview, 7, 100
 - taking over decision-making, 140
- help
 - importance of asking for, 13
 - outside, role in staying in home, 35–38
- hiring driver, 75
- holographic will, 102
- home, staying in current. *See* aging in place; downsizing
- home-based services, 23, 36–37, 87–88, 92–93, 148
- hospice care, 145, 147–150
- hospital care. *See also* advance directives
 - being admitted, 115–116
 - emergencies, 114–115
 - Medicare coverage, 81–82
 - moving to short-term rehab, 125–127
 - overview, 113
 - planning for, 117–119
- hospitalists, 116, 143
- house sharing, 61–62
- housing. *See also* aging in place; assisted living; downsizing
 - changing needs, planning around, 10–13
 - choices for, 59–62
 - creating plan based on profile, 23
 - planning for cost of, 22
 - starting to think about, 6

I

improvement standard, Medicare, 88
independent living for seniors,
26, 60, 75
independent probate, 105

J

joint bank accounts, 96–98

L

later years, navigating. *See also*
personal profile; *specific related*
topics

changing needs, 10–13

changing options, 8–10

creating plan based on profile, 23

overview, 1–4, 5

professional advice, 13–14

reasons to plan in advance,
5–8

lawyers, getting advice from,
13–14

legal changes to long-term care, 9

legal papers, assembling, 42

legal planning, 6. *See also* wills

living wills, 139, 140, 145. *See also*
advance directives

local programs, getting information
through, 154–155

long-term care. *See also* nursing
homes

changes to, 8–10

Medicaid managed, 93–94

Medicare program, 77

state ombudsman for,
52, 135

Lyft, 74

M

managed long-term care, Medicaid,
93–94

Medicaid

basics, 88–89

changes to, 8–9

effect of joint bank accounts, 97

eligibility, 89–91

home- and community-based
programs, 92–93

home healthcare, 36

home modifications, 34

hospice benefits, 148

managed long-term care, 93–94

versus Medicare, 78–79

overview, 77–78

resources related to, 152

services offered, 91–92

medical care. *See* healthcare

medical needs of older adults,
108–111

medically needy programs, Medicaid,
90

Medicare

basics, 79

durable medical equipment, 86–87

eligibility, 79–80

home healthcare, 36, 87–88

hospice benefits, 146, 148–149

hospital care coverage, 81–82, 116

versus Medicaid, 78–79

Medicare Advantage, 83–84

Nursing Home Checklist, 129

Nursing Home Compare, 127–128

Original Medicare, 80–83

overview, 77–78

palliative care coverage, 146

- Medicare (*continued*)
 - Part A, 81–82, 116, 126
 - Part B, 82, 116
 - Part D, 82, 84–86
 - prescription drug coverage, 84–86
 - rehabilitation coverage, 81–82, 126–127
 - resources related to, 152–153
 - surgery-related costs, 119
- Medicare Supplemental Insurance (Medigap), 83, 84
- medications. *See* prescription drugs
- memorial service, planning, 101
- memory care, 51, 129
- modifications to home
 - accessibility, 31–33
 - categorizing types of, 30–31
 - downsizing when making, 41
 - finding contractor, 33–34
 - getting early start on, 12
 - getting help paying for, 34–35
 - overview, 29–30
- modifying vehicles, 69–70
- money
 - attitudes about, 21–22
 - managing, 96–100
- moving, 10–13, 45
- multigenerational living, 23
- multiparty account without a right of survivorship, 97

N

- National Center for Assisted Living, 49
- National Council on Aging (NCOA), 156
- National Hospice and Palliative Care Organization, 156
- Naturally Occurring Retirement Communities (NORCs), 60, 61
- niche communities, 60

- nongovernmental resources, 155–156
- nursing homes
 - changes to, 8–10
 - comparing, 127–128
 - creating plan based on profile, 23
 - defined, 124
 - Medicaid coverage, 91–92
 - Medicare rehab coverage, 81
 - moving from hospital to rehab, 125–127
 - overview, 123–124
 - policy details, 133–134
 - responding to problems in, 134–135
 - type of ownership, 124–125
 - visiting, 128–132
- nursing-home level of care, assisted living, 59

O

- observation status, in hospitals, 81–82, 116, 126–127
- old age. *See* later years, navigating; personal profile; *specific related topics*
- Olmstead v. L.C., 9
- ombudsman, 52, 135
- oral will, 102
- Original Medicare, 80–83, 87
- over-the-counter medications, 120

P

- palliative care, 145–146
- papers, gathering important, 42
- paratransit options, 72, 73
- personal profile
 - attitudes about money, 21–22
 - creating plan based on, 23
 - family, friends, and professionals, 18–19

- healthcare needs, 16–18
- overview, 15–16
- personality characteristics, 19–21
- personality characteristics, 19–21
- pharmaceutical assistance programs, 86
- Physician Orders for Life-Sustaining Treatment (POLST), 144–145
- planning for later years. *See also* personal profile; *specific related topics*
 - changing options, 8–10
 - creating plan based on profile, 23
 - meeting changing needs, 10–13
 - overview, 1–4, 5
 - professional advice, 13–14
 - reasons to plan in advance, 5–8
- policy details, nursing homes, 133–134
- polypharmacy, 119–122
- pour-over will, 102
- prescription drugs, 82, 84–86, 110, 119–122
- private transportation options, 74–76
- probate, 100–101, 104–106
- professionals
 - getting advice from, 13–14
 - in personal profile, 18–19
- profile, personal. *See* personal profile
- public transportation, 72–74

R

- rehabilitation programs, 81, 116, 118, 125–127
- renovations. *See* modifications to home
- resident council, nursing homes, 132
- resources
 - assisted living, 52–53
 - community-based organizations, 155–156
 - federal programs, 151–154
 - online, 2
 - overview, 151
 - state and local programs, 154–155
- retirement accounts, 102
- rightsizing, 39. *See also* downsizing

S

- safety
 - of driving, 64–67, 70–71
 - hazards in home, 26–29
 - in nursing homes, 132
 - technology increasing in car, 68–69
 - when aging in place, 26
- same-sex couples, 80
- scams, 33, 79, 86
- selling household items, 43–45
- seniors. *See* later years, navigating; *specific related topics*
- serious illness, planning for, 137–139. *See also* advance directives; healthcare
- shared control of finances, 96–100
- simple will, 102
- skilled nursing facilities (SNFs). *See* nursing homes
- small-estate probate, 105
- smartphone app car services, 74–75
- Social Security Administration (SSA), 154
- sorting household items, 42–43
- springing durable power of attorney, 99
- state assisted living regulations, 49
- State Health Insurance Assistance Program (SHIP), 78
- state long-term care ombudsman, 52, 135
- state Medicaid plans. *See* Medicaid
- State Pharmacy Assistance Programs (SPAPs), 85

- state programs, as resources, 154–155
- state websites related to assisted living, 52
- state-approved advance directives, 140
- supervised probate, 105
- supplemental transportation programs (STPs), 75
- surgery, planning for, 117–119
- surrogate decision maker. *See* healthcare proxy
- survivorship right, joint bank accounts, 96–97

T

- taxis, 74
- technology, 37–38, 68–69
- transportation options
 - alternatives to driving, 71–76
 - giving up driving, 70–71
 - judging whether driving is still safe, 64–67
 - modifying car, 67–70
 - overview, 63
- treatment decisions. *See* advance directives; healthcare

U

- Uber, 74
- universal design, 30–31
- unsafe driving, 64–65
- unsupervised probate, 105
- urgent care centers, 114–115
- USA.gov, 154

V

- vehicle, making adjustments to, 67–70
- Village concept, 60, 61, 75
- volunteer transportation programs, 75

W

- waiver programs, Medicaid, 92–93
- wills, 95, 100–104

Y

- yard sales, 44–45

About the Author

Carol Levine has taken the “road less traveled” on her career path. As an undergraduate at Cornell University, she studied Russian history, literature, and language, and continued her studies at Columbia University, where she received a master’s degree in public law and government. The link to her current position as director of the United Hospital Fund’s Families and Health Care Project is not immediately apparent, but each step along the way involved honing her skills as a researcher, analyst, and writer.

She was introduced to the world of medical ethics through her tenure at The Hastings Center, where she edited the *Hastings Center Report* and is now a Hastings Center Fellow. Much of her work in the 1980s and early 1990s concerned HIV/AIDS and ethics, and in 1993 she was awarded a MacArthur Foundation Fellowship for that work.

She joined the United Hospital Fund in 1996 to work on issues related to family caregiving, a professional interest that grew out of her personal experience as a caregiver to her late husband, who was disabled as the result of an automobile accident. That work has been recognized by her designation as a WebMD Health Hero in 2007 and a Civic Ventures Purpose Prize Fellow in 2009. She was named one of *Next Avenue*’s 2016 Influencers in Aging. She serves on many advisory boards related to family caregiving and long-term care.

Carol lives in New York City, surrounded by books and needlepoint and, as often as possible, by children and grandchildren.

Publisher's Acknowledgments

Senior Acquisitions Editor:

Tracy Boggier

Project Manager: Vicki Adang

Technical Editor: Mark Friedlich

Production Editor:

Mohammed Zafar Ali

Cover Photos: VICTOR- /

iStockphoto; ganolmc /

iStockphoto; lushik / iStockphoto

WILEY END USER LICENSE AGREEMENT

Go to www.wiley.com/go/eula to access Wiley's ebook EULA.